THE SOCIAL NETWORKS OF PEOPLE WITH END STAGE RENAL DISEASE: COMPARING HEMODIALYSIS AND PERITONEAL DIALYSIS PATIENTS

By

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Gene Ann Shelley

I would like to dedicate this dissertation to my mother, Mary Eleanor (Jones) Welden, who told me I could do anything if I tried hard enough and to H. Russell Bernard, my mentor, who made me believe it was really true.

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Abstract of Dissertation Presented to the Graduate School of the University of Florida in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy

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By

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The lives of people who have End Stage Renal Disease (ESRD) and as a result are on dialysis are usually restricted in some way, and they tend to rely heavily on their social network members for assistance. This assistance can include helping the dialysis patient to accept dialysis and better comply with diet, medication and dialysis regimens.

Researchers often measure a patient's "social support" to discover whether social support has any effect on health outcomes. Unfortunately, social support is often directly equated with the quantity of available social network members. Social support variables have also been used as a combined index of social network structural variables and

variables of coping or adjustment. This mixture leads to inconclusive results.

This research compares the social networks of hemodialysis and peritoneal dialysis patients to determine how their social networks differ and if there are network properties which affect patient health outcomes. Individual measures of network structure, including density, reciprocity, multiplexity, duration of relation and strength of social tie are used as independent variables to predict patient health outcomes. These outcomes include serum blood chemistry values and ratings of physical and mental health status. Among the instruments used to evaluate mental health status were the Profile of Mood States and the Multidimensional Health Locus of Control.

Social network structural variables were found to correlate with positive health outcomes. Network density was a significant structural variable predicting lower levels of depression. Although there were some differences in type of dialysis, gender and racial groups were sometimes more predictive of health outcomes. Multiple regression results also corroborate this. Dialysis patients were found to have much smaller social networks than healthy people and this may put these patients at a disadvantage.

Some suggestions were offered for improving the quality of life and compliance of ESRD patients through social network intervention.

CHAPTER 1
INTRODUCTION

The Scope of the Problem

In 1990, there were 129,800 End Stage Renal Disease (ESRD) patients in the United States; 106,573 (82%) of whom were on in-center hemodialysis (HD). Of the other 23,000, almost 21,000 were on some form of peritoneal dialysis (PD), including Continuous Ambulatory Peritoneal Dialysis (CAPD), Intermittent Peritoneal Dialysis (IPD) or Continuous Cycling Peritoneal Dialysis (CCPD). A very small group of dialysis patients (under 2,500) were on home hemodialysis (U.S. Dept. of Health and Human Services Research Report 1991). End Stage Renal Disease is very expensive, and most patients receive some Medicare payments. The bill came to almost three billion dollars in 1988 and by the year 2000, at the current rate of inflation on medical care costs, the public tax obligation will exceed twelve billion dollars.

Many people who have ESRD also have other problems, such as diabetes, hypertension, pulmonary edema, congestive heart failure, blindness, systemic lupus erythematosus (SLE), sexual dysfunction, stress and depression. They are often in dire financial difficulty and are usually out of

work. Their family members experience stress, that, in turn, may make it even more difficult for ESRD patients to thrive (Fortener-Frazier 1981; Nissenson 1984).

ESRD--A Major Health Problem

Before March 9, 1960, when the first arteriovenous shunt was implanted in the arm of a kidney patient, a diagnosis of ESRD was a death sentence. "'Suddenly,' the physician observed, 'we took something that was 100% fatal and overnight turned it into 90% survival.' To say the least, no one was prepared for it" (Massry 1990:10).

In 1972 and 1973, legislation was passed which declared everyone with a diagnosis of ESRD to be eligible for Medicare and Medicaid funding (Massry 1990). Aside from helping patients with astronomical medical bills, one of the intentions of these laws was the rehabilitation of patients so they could re-enter the workforce. Unfortunately, this does not occur frequently and most dialysis patients are unemployed.

Many people who have kidney disease go on to develop other life-threatening problems. In fact, kidney disease is "one of the major contributing factors in heart disease, causing an astounding number of deaths through stroke, heart attack, and hypertension" (Massry 1990:11).

Kidney disease does not only affect the patients who have it. It is a disease with far-reaching effects. The

lives of family, friends and those who care for kidney patients are all affected. Although dialysis saves and prolongs lives, it costs a lot of money and does not completely alleviate human suffering. The type of dialysis procedure that a patient receives may make a difference in the quality of life of ESRD patients.

Kinds of Dialysis Procedures

There are several kinds of dialysis which an ESRD patient can choose. The main two types are hemodialysis (which will be referred to as HD) and peritoneal dialysis (referred to as PD). There are advantages and disadvantages to both kinds, and these main types will be compared throughout this dissertation.

Hemodialysis. Patients on HD normally go three times a week to a clinic or center. They spend about three hours during each visit, connected to a machine, while their blood is cleansed. To prepare a patient for hemodialysis, a surgical procedure is done wherein an artery and vein are stitched together (called a "fistula") and surgically implanted inside the arm or occasionally the leg. During HD, two needles are inserted into the fistula and attached to the tubes of the kidney machine so that arterial blood can be circulated from the patient, into the artificial kidney, together with a dialysis solution. Inside the machine, the blood is filtered by a cellophane membrane and

comes back into the body through a nearby vein. The needles used for this procedure are large 15-gauge needles. They appear to be about the size of small knitting needles. They can be quite painful. There is always some loss of patient blood into the machine. Thus, HD patients are often anemic and as a result may have to have blood transfusions.

Patients on HD often complain of dizziness, nausea, headaches, itching, leg cramps and lack of energy during and after hemodialysis. These symptoms and the patients' dialysis schedule make it difficult for them to remain employed (Czaczkes and Kaplan DeNour 1978; Chyatte 1979; Jungers et al. 1973).

Peritoneal dialysis. Patients who use Continuous Ambulatory Peritoneal Dialysis (CAPD), the most common form of peritoneal dialysis, cleanse their own blood at home four or five times per day. This is done by inflowing approximately two liters of dialysis fluid via a 25-30 centimeter long catheter which has been surgically implanted into the abdominal cavity. The catheter provides a permanent access site for infusion of dialysis fluid. This fluid is infused into the peritoneal cavity and "dwells" for four to six hours per exchange. The presence of the fluid allows a concentration gradient to exist between the circulating blood on one side of the peritoneal membrane and the dialysis fluid on the other. The peritoneal membrane is semi-permeable and filters out accumulated solutes

(creatinine, potassium, phosphorous, etc.) which the failed kidneys can no longer filter. The rate at which these solutes are filtered out is called "clearance." After inflowing the fluid, the patients roll up the empty bag, keeping it on their person, while the filtration process takes place in their abdomen. The fluid remains in the abdomen for about four hours each time during the day and for about eight hours while the patient is sleeping at night. At the conclusion of this filtering period (the dwell time), the patient releases the filtered fluid through the catheter and into the empty bag by the force of gravity. This procedure, called an "exchange," does not require a machine and takes about half an hour each time it is done. There is no blood loss with CAPD and no pain associated with connection of the catheter to the dialysate bag. The dialysis time itself is longer for CAPD than HD, but the patient can be doing other things during the day while the dialysis procedure is going on.

Peritoneal dialysis patients do not usually have the adverse physical symptoms experienced by HD patients because the toxins are removed from the blood at a more continuous rate than with hemodialysis. People on CAPD have less disruption of lifestyle and many hold jobs (Beardsworth and Goldsmith 1984). Patients who use another form of peritoneal dialysis, Continuous Cycling Peritoneal Dialysis (CCPD), are even more likely to be able to work. On CCPD,

the patient is dialyzed during sleep. The patient's peritoneal catheter is attached to a machine which automatically warms the bags of dialysis fluid and inflows them into the patient. During one night's sleep, a patient will use several bags of dialysis fluid. On CCPD, the patient must stay in bed for a solid eight hour period at night. For those patients who are employed, this necessitates an almost inflexible bedtime.

Overall, peritoneal dialysis (PD) is less expensive than hemodialysis (HD), but it has some disadvantages. The CAPD patient must have a sterile area at home for dialysis and must exercise other precautions to avoid infection, including strict body cleanliness and special care of the abdominal catheter. Despite precautions, patients can get life-threatening peritonitis which requires hospitalization. Patients sometimes have an adverse body image because of the implanted catheter and attached dialysis bag, which can affect personal relationships. The family is more aware of the dialysis process when it occurs at home and this can increase family stress. Consequently, some patients do not want to dialyze in their homes and prefer to have clinicians do the dialysis for them. Peritoneal dialysis patients are responsible for their own dialysis and are in control of their own time schedules.

Frequency of dialysis can affect how a patient feels. Peritoneal dialysis removes uremic toxins at a more regular

rate so these patients are not subject to headaches and nausea caused by HD. However, HD cleanses the blood more efficiently than PD. Although both types of dialysis cause a patient to lose protein, the loss is more severe with PD. Therefore, PD patients must be monitored closely for signs of protein deficiency and malnutrition. Loss of appetite, caused by a feeling of fullness due to dialysis fluid in the abdomen, can also contribute to nutritional problems. Some patients who try PD are not able to continue with it. Health care workers screen ESRD patients carefully for those whom they think will be able to handle self-care successfully.

The Importance of the Social Network

People interact with others on a daily basis to get emotional support, information, advice, help with tasks, etc. These interactions form a "social network" which is a construct enabling us to envision what is called "social structure" (Radcliffe-Brown 1952). Although "social structure" cannot be seen, scientists have theorized that it may have an effect on human behavior.

A person's social network is composed of friends, relatives and acquaintances. Some network members are "close" and some are not. "Close" social network members are called "strong" social ties in the literature (Granovetter 1973; 1985). Researchers have found that

people with strong ties are more likely to be physically and mentally healthy (Lin, Woelfel and Light 1985; Cohen and Sokolovsky 1979; Hammer 1983). However, "weak" social ties are also important for the transmission of information. In other words, we need both "strong" and "weak" ties, although research continues on what a "healthy proportion" of these ties might be under various life circumstances.

In addition to strength of relation, researchers have identified and measured various other attributes of social networks. These attributes include centrality (Freeman 1979), transitivity (Holland and Leinhardt 1983), density (Barnes 1969; Mitchell 1969) and multiplexity (Kapferer 1969), and they describe the structure of the network. These structural properties and, indeed, the entire structure of a social network, are presumed to influence the regular behavioral patterns of individual network members (Berkowitz 1982).

People with ESRD, more than most people, depend on a few social network members for survival. Their strong ties (immediate family, for example) provide help with daily chores, emotional support, advice, some transportation and even, on occasion, a lifeline to emergency services. Their weak ties (clinic staff members and other patients with whom they chat during the long, boring hours on the dialysis machines) provide information and companionship.

Families of ESRD patients sometimes help the patient decide what kind of dialysis to initiate and also whether or not to put themselves on the transplant list. At times, family members may be asked (or volunteer) to give up one of their own kidneys for transplantation into the patient.

Even PD patients, who are the most independent of others, need someone to deliver supplies to their homes. They also rely on consultation by telephone with nurses and doctors when they have problems. Many PD patients also have help from family members with their actual dialysis. Family members can help the patient by warming the dialysate bags in the microwave so the fluid will be body temperature when it enters the patient. Warmer dialysate makes the filtering more efficient and is more comfortable for the patient. Some family members even do the entire dialysis procedure for the patient. This is usually when the patient for some reason cannot exercise self-care.

People with ESRD have to have other people in their lives, even if they are only weak ties. However, these patients may not have as many social network members as do people who are not chronically ill. Dialysis, visits to clinics for check-ups, and actual hospitalizations take up time which might otherwise be spent with friends and relatives. Most ESRD patients, regardless of dialysis mode, experience some energy loss and, consequently, do not feel like being with others. Because much of the time they feel

ill, some ESRD patients can be difficult and demanding. And some healthy individuals do not like to be around sick people. Of all groups who really rely on others, dialysis patients seem to me to be an ideal group to discover whether there is any relationship between inherent social network properties and behavioral outcomes. Therefore, this research was designed to understand whether, and how much, social network properties influence the health conditions of ESRD patients. The primary question I want to answer is: "Does an individual's social network make any difference in the health outcomes of that individual on (either type of) dialysis?"

On balance, HD patients seem to be far more dependent on others than are PD patients. Are the social networks of HD and PD patients different? If so, does this cause them to behave differently from one another? Are health outcomes better for peritoneal patients, who may have a more "normal" life?

Some patients do better than others: they take their medicines on time; they watch their diets more carefully; they exercise; they are more socially active; they have a better attitude; they are not depressed and they just feel better. A great deal of time and money is invested in keeping dialysis patients alive and trying to improve their quality of life. Could social network structure make a difference in this? If the structure of the social network

does make a difference, then perhaps the network could be used to help improve health outcomes and quality of life of ESRD patients.

CHAPTER 2
SOCIAL NETWORK THEORY

Social Structure and Social Networks

For many years, researchers have been interested in social structure and the nature of social relations. Spencer (1906:440) discussed social systems and their "coordinating structures and functions." He looked at the relationship between the structure and how its parts worked with an "inter-dependence of structures, functions and products" (Spencer 1906:442). Spencer used a biological model to try to describe how individuals were able to work together in cooperation. Durkheim (1938) theorized that the components, or members, of a social group could combine to form an entity which had its own characteristics. That entity created is called social structure. Social structure has been thought by many to have an effect on the individuals embedded inside it. That is, the group of people an individual associates with has some influence on the behavior of that individual. The idea of group influence on individual behavior has been around for a while. Bavelas (1948, 1950) studied communication patterns and found limitations on group structure had an influence on

outcomes. He used mathematical properties and diagrams to illustrate his findings.

A heated debate in the field of anthropology arose over the inner workings of social structure. The three primary participants in the debate were Claude Levi-Strauss, A.R. Radcliffe Brown and Bronislaw Malinowski. The latter two were empiricists who believed that social structure should be discovered by observation of the people in it, while Levi-Strauss believed "social structure has nothing to do with empirical reality but with models which are built up after it" (Levi-Strauss 1963:279). Levi-Strauss is associated with the "structuralist" theoretical point of view in anthropology. In this view, the structures of a society or group are in place and work for the survival of the group (i.e. marriage rules). These structures exist in the subconscious thought of individuals in the group and guide their behavior.

One main theoretical focus for looking at social structures was "functionalism." Malinowski (1944) is thought of as the father of "functionalist theory." His perspective of functionalism was that cultural habits functioned for the individual. He saw basic human biological needs as having to be solved or satisfied. The way they were satisfied explains the function of cultural habits.

Others, such as Radcliffe-Brown, looked at functionalism in terms of the society as a whole. Although Radcliffe-Brown was associated with the founding of functionalism, he rejected that association. He was interested in how social structure functioned for the society, and not specifically for the individual in it. In fact, he expressed the view that the individuals in the structure could change but that the structure would remain. Thus, Radcliffe-Brown's type of functionalism is called "structural-functionalism." Structural-functionalists describe how people and structures influence each other. Unlike the mental structures of Levi-Strauss, Radcliffe-Brown discussed social structure as a "network of actually existing relations" (Radcliffe-Brown 1965:191). He considered individuals in the social structure as "part of a wide network of social relations, involving many other persons," and he regarded the network as the object of investigation (Radcliffe-Brown 1965:191). He stressed the importance of studying people individually and as part of their environment as an active process. He did not think it was sufficient to just study the positions of people in their environment (structuralism), nor the environment as it functions for individuals (functionalism). By environment, I mean all the dimensions of it: physical, social and psychological. He apparently saw the network of social relations as being predictive of people's behavior.

Other researchers were also interested in the relationship between the structure of social relations and how it functions for individuals. As Merton (1957:136) said, "structure affects function and function affects structure." This view is held by social network analysts. They believe that there is something about the structure of social relations that can have an effect on human behavior. Researchers using social network theory are sometimes maligned for using social network methods without a codified body of theory. However, social network theory is developing. Mostly through trial and error, investigators using social network methods have learned a great deal about the components of social structure, although there is much more to know. It is better to find out some things than nothing at all. Nadel (1957:154) said, "we profit not from having defined a social structure, but from trying to define it."

The Social Network Paradigm

Scott (1991) describes three influences on social network theory. The first influence was the work of Moreno (1934), Lewin (1936) and Heider (1946), social psychologists who used mathematical methods and theories in their research on how individuals perceive relations with fellow group members and how those perceptions affected behavior. Moreno started the journal Sociometry and invented the "sociogram,"

which shows "patterns of interpersonal choice" (Moreno 1934:9). Others who were working on mathematical structures of group relations in this early period included Bavelas (1948, 1950) and Harary and Norman (1953).

The second influence on the development of the social network paradigm was the theoretical influence of Radcliffe-Brown on several researchers who were studying social interactions. Two of these, W. Lloyd Warner and Elton Mayo, worked together at the University of Chicago. Mayo worked on the Hawthorne studies of the famous "bank wiring room." The research report on this can be found in Roethlisberger and Dickson (1939). Mayo and Warner's anthropological input in the project led to diagrams of social interaction and group structure which looked like Moreno's sociograms; however, they did not refer to Moreno in their work (Scott 1991).

On the other hand, George Homans used Moreno's sociograms to illustrate his theories on human interaction. Homans talked about interactions having attributes such as frequency, direction and duration. Homans reanalyzed the Hawthorne data (Homans 1951:83) and used primitive blockmodeling (although he did not call it that) to reshuffle clique diagrams so that patterns could be detected.

The third influence on the beginnings of social network theories was the work of British anthropologists John

Barnes, Clyde Mitchell and Elizabeth Bott at Manchester University. They too, were influenced by Radcliffe-Brown. Also at Manchester was Max Gluckman, who was interested in conflict and power in social interactions. These anthropologists saw structures as "networks of relations" and "combined formal techniques of network analysis with substantive sociological concepts" (Scott 1991:27). These researchers were still emphasizing personal relations as did Parsons (1951) and so "social network analysis could not help but be seen as a specialized area of study rather than a critical alternative to conventional sociology" (Scott 1991:27).

At first, Barnes and others used "social network" in a metaphorical sense. However, Barnes (1954) found that people actually used network connections to get desired positions on fishing boats. Their networks mostly contained people of similar social class but class lines were blurred when people used their connections to get jobs. Barnes noted that people were able to influence lawmaking committees, both directly and indirectly, through network members. Bott was influenced by this study to also use social network methods as an analytical tool. She studied the relationship between social networks and family role behaviors and found a correlation between network density and type of conjugal role (Bott 1957). Bott had studied anthropology with Lloyd Warner and was no doubt influenced

by him and Lewin. Both Bott and Barnes cited Moreno in their work. Bott and Barnes had an influence on Siegfried Nadel who talked about social structure as "an overall system, a network or pattern of relations" (Nadel 1957:12). Nadel thought it best to use a "mathematical approach to structure" (Scott 1991:30).

This period in network analysis was a time in which everyone seemed to be defining terms and realms which might be useful for network analysis. Clyde Mitchell (1969) talked about two kinds of network analysis: ego-centered and global networks. He concentrated on the ego-centered type. Mitchell described various network properties such as reciprocity, durability, intensity, reachability and density. Bott and Barnes used the concept of density in their work but called it something else.

In the classic statement, Mitchell defined a social network as a "specific set of linkages among a defined set of persons, with the additional property that the characteristics of these linkages as a whole may be used to interpret the social behaviour of the persons involved" (Mitchell 1969:2). It is the interpretation of social behavior, and actually the prediction of human behavior, which is the goal. Mitchell also stated that two people could be expected to behave in a certain way because of the roles they occupy. In addition, "variations in the behaviour of people in any one role relationship may be

traced to the effects of the behaviour of other people, to whom they are linked in one, two or more steps, in some other quite different role relationship" (Mitchell 1969:46). Mitchell was saying here that the behavior of individuals was due to the structure in which they were embedded and also the combined structural influences of other network members.

Mitchell differentiated between structures of institutional relations and the individual interpersonal relations going on inside those institutional relations. This made social network analysis a "special method for the analysis of interpersonal relations" (Scott 1991:33) instead of a general method of analysis. Thus, social network analysis came to be known in Britain only for ego-centered networks.

Mitchell was one of many researchers who were concentrating on the individual network links and their properties. Epstein (1969a, 1969b) noted the importance of the quality of relations and distinguished between the "effective" network, those with whom a person "interacts most intensely and most regularly" (Epstein 1969a:110) and the rest of the network, the "extended" network. Note that Epstein's usage was contrary to today's usage. We speak of the "affective" network as consisting of those closest to ego and likely to give emotional support, while "effective" relations are those who provide material support such as

money, transportation, etc. Epstein (1969b) also found that community gossip shaped social class attitudes and behaviors.

Kapferer (1969) and Wheeldon (1969) saw the strength of individual network ties as reflected by multiplexity, which is the number of social contexts in which each network member is associated with "ego." In addition, stronger ties are better able to reinforce network norms and exert more influence over the whole network. However, Boswell (1969:254) stated, "what matters as much as the intensity of the relationships and the interconnectedness of the members of the network is the content of those relationships." He looked at how network members may be called upon to help each other in times of crisis. Other studies on how networks help individuals are called the study of social support.

Up to this point network studies seemed to involve describing and mapping networks, but not much emphasis was placed in seeing how network structures worked. Milgram (1967) began working on the problem of determining the structure of the network. He asked people (called starters) to pass packets of information to others (called targets). If the starters did not know the targets, the starters were to pass the folders on to the most likely person they knew who might know those targets. Milgram calculated how many people the folders had to pass through before they were

received by the targets. Milgram found that for any two people in the U.S. there are on average, five intermediaries. In other words, these people have "five circles of acquaintances" between them. His study shows that "in some sense, we are all bound together in a tightly knit social fabric" (Milgram 1967:67).

Though their paper was not published until 1978, Pool and Kochen began 20 years earlier to work on network structure. They proposed that social relations are not random, but they are due to the social structure in which one is embedded. An individual in a particular structure can influence or be influenced by those in the surrounding network, either directly, or through others. Pool and Kochen proposed questions which they hoped would illuminate the structure of networks. They wanted to know the size and composition of networks and how likely it would be that two people who did not know each other would have a friend in common. They proposed that if two people knew person (A), the chances are more likely that they know each other than if they did not know person (A). In their experiment, Pool and Kochen found that people tend to know others like themselves. This is the theory of homophily. Pool and Kochen also found that people saw a regular set of network members and a set they saw by chance. This suggested to the researchers that "there is a pool of persons with whom one is currently in potential contact and a larger pool in one's

memory" (Pool and Kochen 1978:28). Pool and Kochen also used mathematical models and graph theory to try to be more precise in their explanation of social contact.

Holland and Leinhardt (1970) continued in this mathematical modeling vein in discussing the principle of transitivity. This principle is that if person A knows person B and person B knows person C, then A also knows C. A network can be described as being relatively transitive or intransitive and thus whole networks can be compared.

At about this time, Harrison White and others at Harvard began to publish papers which used "social network analysis as a method of structural analysis" (Scott 1991:33). The stage for these papers was set by the development of two areas of mathematics. First, set theory was used to model the concept of "role" algebraically (Lorrain and White 1971). This is accomplished through blockmodeling and structural equivalence, which are ways of comparing social structures. Secondly, multidimensional scaling methods were developed for mapping social distances on paper. After this, mathematical modeling of social structure was done for its own sake, without particular theoretical guidance (Scott 1991).

Also, during the 1970s, researchers were still defining network properties of individual networks and the types of network relations which would be most responsible for moral sanctions and perpetuating network norms (Kapferer 1973;

Mitchell 1973; Neimeijer 1973; Cubitt 1973; Boissevain 1973; Banck 1973). Many of these researchers emphasized that individuals make choices about network relations and that people can manipulate their networks and be manipulated by them. However, some of these researchers also began to place a greater emphasis on structural network matters (Boissevain 1973).

Especially in regard to urban networks, Craven and Wellman (1973) studied the structural properties of a network. The measurement of various dimensions of network relations was becoming more prominent. Some analyses became highly quantitative and parts of the analyses were not understandable by some non-mathematicians (Burt 1983, Freeman 1978, Berkowitz 1982). Other measurement problems are conceptualized and almost taken for granted. For example, Granovetter (1973, 1982) examined the strength of social tie to see if it was a valid conceptualization of relation intensity. Other researchers (Friedkin 1980, 1982; Hansell 1984; Marsden and Campbell 1984; Murray 1982) have incorporated the concept of tie strength in their research and found it to be a valid conceptualization.

Some researchers have addressed other data measurement questions such as data reliability (Conrath 1983) and accuracy (Bernard and Killworth 1977; Bernard et al. 1979, 1982a, 1984; Killworth and Bernard 1976, 1979). Network analysis has also expanded to study entities, such as

corporations (Burt 1982) to try to view social structures which affect the individual in even broader ways. Network analysts seem to have clear conceptions of what a network is and how a network might function as an independent variable in research.

Current Status of the Paradigm

Researchers using structuralist theories in anthropology were able to represent kinship structures very well. However, they were not able to provide explanations for changing complex societies (Foster 1978) as social network analysis can do. Social network analysts quantify and measure social structure. In addition, they measure the "interactions" involved, using measures of density, centrality, direction, etc. Structuralists usually would look at behavior in only one sphere of activity (i.e. kinship system, religious system). Social network analysis can take into account many different spheres of activity at once (Mitchell 1969).

One of the ways network analysis does this is by the idea of structural equivalence. Structural equivalence means that two individuals may be expected to behave similarly because of their structural position in relation to other people. This is because similar types of people are exerting similar types of influence on them. Thus, managers at a certain level in a corporation would be

expected to generally behave in a certain way toward those structurally higher or lower than they in an organization. Two people in the same social stratum may be expected to behave generally similarly toward members of different social stratum. Of course, there is individual variation within the structure. But those variations are likely to be more similar to each other the more alike the attributes of the surrounding network members are. This seems intuitively correct and it also works in practice. For example, Harries-Jones (1969) reports that African migrants to the city still interacted with the elders (who had also moved to the city) in the same way as they had in the rural areas, even though the context was different.

Social network research is valuable for studying dynamic processes. One of these processes is resource exchange. Resources could be wealth, influence, jobs, information, or emotional support (Wellman 1988).

Researchers have given many insights into the workings of social structure. Certain principles of social interaction have been researched and accepted as part of the theoretical base of social network analysis. Some of those findings are 1) social networks are homophilic; 2) network membership cuts across class lines; 3) network members influence each other both directly and indirectly in attitudes, group norms and behaviors; 4) stronger ties are better able to reinforce these norms and exert more

influence over the whole network; 5) weak ties are important in obtaining information and resources; 6) there are measurable network properties such as reciprocity, durability, intensity, density, transitivity and reachability; and 7) there have been improvements in data reliability and accuracy.

Unfortunately, the development of a paradigm of social network research, including the full complement of method and theory, has been slow to appear. However, Hummon and Carley (1992) recently studied literary citations in various journals used by social network analysts to find the major influences and core research areas. They concluded that the paradigm of social networks is in Kuhn's "developed" stage and that social network analysts are engaged in "normal science" as defined by Kuhn (1970).

The development of a paradigm of social network research has been hampered by the fact that some researchers have concentrated on the structure of a social network at the expense of developing theories to guide research. Structuralists have concentrated on mathematically and visually representing the social network. Functionalists operate in the realm of social support. They talk about how "significant other" people mediate or buffer stressful situations for others; however, functionalists do not consider the social structure of those significant others. To be really effective, social network research needs to be

able to synthesize the two approaches. It seems that structuralists concentrate on method while social support enthusiasts concentrate on the theories of how networks can be helpful. According to Kuhn (1970), a new scientific paradigm will form when two things happen simultaneously. First, the subject matter has to be sufficiently different from existing paradigms and also there have to be problems for this new paradigm to solve. In social network research, Kuhn's first condition was not met. Social network research was built on the theories already being used in many disciplines (i.e. economics, sociology, health care delivery, psychology, management, business, communications and anthropology). Researchers in these fields just applied their own theories to the study of social networks. They were not forced to develop separate theories and models to study social network relations. The early result in social network studies was a flood of descriptions about measures and properties of social networks in order to try to describe how to use the concept of social networks in research. Kuhn (1970) further explains the life cycle of a scientific paradigm in that if there is no developed paradigm all aspects of the paradigm seem equally important. So researchers in a developing science start wildly gathering data about all kinds of things without a particular focus. So far that was what happened in the development of a social network paradigm. Researchers have

been concentrating on methodology, at the expense of trying to codify a body of theory to go with it. Some researchers have noticed the lack of specific theory behind social network research, and there have been several recent works on theory (Knoke and Kuklinski 1982; Berkowitz 1982; Wellman 1988; Wellman and Berkowitz 1988). These researchers propose that the structure of the whole network system can influence the behavior of the individual actors. If the structures are modeled in the same way and with the same theoretical considerations, they can be compared and conclusions made (Berkowitz 1982).

There are two ways to examine networks. One way is to look at the attributes of the individual actors and combine them to form a view of network structure. In this model, the social network would be the dependent variable in research. That is, the attributes of the individual actors affect the composition of the whole network. The other theoretical perspective is that the attributes of the individuals in the network are affected by the structure in which they are embedded. In this view, the social network is an independent variable. In both models, the interactions of individuals and their social structure are studied. The content of these interactions is very important in social network research.

Wellman and Berkowitz (1988) would prefer that the name "structural analysis" be used instead of "social network

analysis." They state that social structures can be represented as networks which are a set of nodes interconnected by ties. If the concentration is on structures and how they affect things, then the emphasis will be away from the social network jargon of the past. Of course, they realize that the originators of social network analysis wanted to distance themselves as far as possible from the "structuralism" found in sociology and anthropology.

A major factor in lack of development of a social network paradigm is research in the area of social support. This research will be discussed in a later chapter. In general, researchers in this area have used social support indexes instead of social network variables themselves. This makes the results of their studies confusing and inconclusive.

Scott (1991:38) still views social network analysis as a "particular set of methods and not a specific body of theory." Barnes and Harary (1983), said Scott, "have argued that it is possible to advance from the use of formal concepts to the use of formal theory" (1991:37). Social network analysis must go beyond the description of networks. To do that, Barnes and Harary (1983) advocate the use of mathematical theorems in studying relational data.

My Contribution to Social Network Analysis

I believe that social network analysis is really a form of evolved structural-functionalism. Social network theories are rooted in anthropology and sociology and evolved from the structural-functionalism of Radcliffe-Brown. Kapferer (1969) discussed structural-functionalism as being able to deal with norms; however, the individual variation within is obscured. Social network analysis is able to deal with these individual differences and to deal with the entire structure as well. Thus, it advances a step beyond structural-functionalism.

McCord (1980:382) argues that, "we ought to think of network analysis as a versatile and conceptually fundamental enterprise of which structural-functionalism is one potential fragment. Structural-functionalism, in other words, is a network theory." However, it would seem that the pattern of evolution would go in the other direction. That is, since structural-functionalism was an identifiable theory before any social network theories, social network analysis is the result of structural-functional ideas. Inadequacies in that theoretical framework caused researchers to look for better explanations. Thus, social network analysis was born of structural-functionalist theories but is more versatile and can help explain individual behavior. Structural-functionalism was used to try to explain how cultural behaviors maintain the social

structure of the group. However, network researchers theorize that network structure can influence the behavior of the individual actors.

In some disciplines, like physics, the rules were formed very quickly (although the laws of physics developed over hundreds of years). It did not take hundreds of tries to develop a theory and make a rule that if you throw something out of a window, it will go down and hit the ground. That is because there were regular and systematic causalities. Unfortunately, in the case of social network analysis the cause and effect relationships have not been that clear and they may never be. One main contributing problem is that of researchers using different measurements and different definitions. Perhaps if a large body of systematic research is done, with uniform measures and concepts, there may be some progress made.

Although there are problems with the social network paradigm, if such a thing exists, it is still useful as a method. I believe that study of social networks has a potential for practical use, especially in predicting health outcomes. It is easy to say social networks cause everything or social networks cause nothing. It is harder to find out the real relationship between the two. I am using the structural properties which emerge out of network interactions to discover cause and effect between the social network and health. There may be no relationship between

social network structure and any health outcomes. But if there is a significant relationship, perhaps this information could somehow be used to improve the health and quality of life of chronically ill individuals. One other group of researchers (Nissenson 1984; Walcott and Nissenson 1988) used some of the same social network instruments as I did. However, the focus and theoretical reason for using them were different. They were studying differences in adaptation to different dialysis regimens based on social network and psychosocial variables. I do not know of any other research being done at present which asks whether pure social network structural variables determine in some way the health outcomes of patients.

CHAPTER 3
SOCIAL SUPPORT AND SOCIAL NETWORKS

Definition of Social Support

There is a vast body of literature on social support and its effect on health. Unfortunately, there are about as many definitions of social support as there are authors who write about it. In general, social support is viewed as the ability of the social network members to do things for an individual. One of my favorite definitions is by Caplan (1974:6) who describes a social support system as "a kind of island of stability and comfort in the turbulent sea of daily life."

Cobb (1976) defined social support as an information-disseminating process which facilitates coping. He based his theories on examination of research in which social support seemed to have an effect on pregnancy complications, tuberculosis, asthma, peptic ulcer, arthritis, alcoholism, suicide, and depression. Other comprehensive studies and definitions of social support can be found in Caplan (1974), Cassel (1973, 1976), Kaplan et al. (1977) and Israel (1982).

In general, the presence of social support is thought to have a buffering effect on stress and be instrumental in

the proper recovery from illness (Dean and Lin 1977; Pilisuk and Froland 1978; Hammer 1983; Lin et al. 1985). Social support is also thought to moderate stress (Cobb 1976) or influence resistance to disease (Cassell 1976).

Specific Benefits of Social Support

Social Support and Health

Some researchers found social support to be influential in specific situations. Syme et al. (1964) investigated the effect of social support on coronary heart disease. Nuckolls (1972) found that women under stress had one-third less pregnancy complications when they had adequate social support. Morrow et al. (1981) found a correlation between social support and psychological adjustment by parents whose child had cancer. Studies by Dressler (1983, 1986a) show the presence of psychosocial resources mediated the effects of obesity and hypertension. Psychological support was measured by an index created from the number of kin available, the quality of social relations and the coping abilities of the subjects. That is, people who had more psychosocial resources had lower blood pressures. These studies were done with populations that were normally at risk for high blood pressures, either by being obese, or being black.

Another study by Dressler (1986b) used a culturally sensitive index of psychosocial resources for Mexican cultures. Here he found that lower blood pressure in males was associated with having support from compadres. As a result of this study, Dressler stressed the need for measures of social support to be relevant to the particular culture to be studied. Both these studies indicated that having a sufficient number of kin around and having good relations with them was helpful in lowering blood pressure.

There are a number of studies showing how social support is helpful at a particular time in life. However, there have not been many longitudinal studies of the effects of social support. One notable exception was a study by Berkman and Syme (1979). This study looked at 6,928 residents of California from age 30-69. Berkman and Syme consulted the California Death registry 10 years later to see how many of the sample residents had died. Informants initially answered a questionnaire on how many close friends and relatives they had and how often they were in contact with those friends and relatives. For both men and women, over all age groups and socio-economic classes, those who reported more friends/relatives and who saw them frequently had lower mortality rates. Also those who were married, belonged to some type of informal group, or belonged to a church or temple also had lower mortality rates. Deaths were due to a number of different causes, including heart

disease, cancer, cerebrovascular and circulatory diseases, digestive and respiratory diseases, accidents and suicide. The results of this study showed people with more social ties had significantly lower mortality rates even when controlling for such factors as: smoking, obesity, alcohol consumption, physical activity, amount of "good" health practices, or use of medical services. It also did not matter whether the social ties were friends or relatives; the groups appeared to be interchangeable with regard to effect on mortality rates.

Social Support and ESRD

There have been several studies on the effect of social support for people with ESRD. One longitudinal study (Friend et al. 1986) looked at support group membership of 126 black hemodialysis patients, and found after 10 years, those who had participated in the groups were significantly more likely to be alive than those who did not participate.

Hilbert (1985) investigated the possibility of social support helping ESRD patients comply with medical regimens. He looked at 48 patients and measured their social support using a questionnaire which asked the degree of supportive behaviors engaged in by one significant other. He found an indication of significant positive influence by that person on compliance. However, there was a negative correlation between compliance and time on dialysis. Perhaps patients

got lax as time went by and the threat of death was not uppermost in their minds and so they developed non-compliant behaviors. Hilbert proposed that if the "significant other" and the patient were reindoctrinated to the importance of patient compliance there might be some improvement shown in dietary compliance.

Most ESRD patients have at least one "significant other" whom they can confide in and is a source of social support. Siegal et al. (1987) measured social support, both quantitatively and qualitatively, in 101 HD patients, and found that 80% had a "confidant" to talk to who was either a friend or a spouse. Social support quality (helpfulness), but not the quantity (measured by frequency of interaction) was positively associated with adjustment to dialysis.

Kidney patients are generally depressed at one time or another during the course of their illness (Mueller 1980; Kutner et al. 1985; Burton et al. 1986; Israel 1986). In fact, ESRD patients have much more depression than the general population (Craven et al. 1987; Petrie 1989). Most of the studies on depression and chronically ill patients (including ESRD patients) mention the value of "social support" in mediating illness (Errico et al. 1990). However, not all members of a person's social network are supportive. Some are "destructive, insignificant or even innocuous" (Hurd et al. 1981). Several researchers have found that people who manifest symptoms of mental illness,

including depression, have smaller networks than normal people. In fact, the more psychotic, the smaller the network size. Social network therapy has been conducted to work with the person's primary network to change network structure and function to improve mental health (Sokolovsky et al. 1978; Pattison et al. 1975; Pattison et al. 1981; Llamas et al. 1981).

Most of the time researchers think only of the services that a social network member can provide to a person who is ill. However, being able to give as well as receive support can be "empowering" to a chronically-ill person such as an ESRD patient, especially because the ill person may feel dependent and useless in other parts of their lives (Rounds and Israel 1985). Therefore, it is important to look at the reciprocity of support when assessing the mediating value of network interactions to help patients cope with illness.

Social network structure and functions change constantly. Being diagnosed with ESRD makes a definite change in the composition of a person's social network (Chyatte 1979). Therefore, Dimond (1983) suggests that the social network that is useful and helps the kidney patient adapt when the illness is first discovered may not be the same one needed when the patient adjusts to the limitations renal disease makes on life. In fact, the divorce rate is high for ESRD patients. Some physicians have observed that there is an increase in divorce after the ESRD patient's

condition has stabilized to what it will probably be for the remainder of the patient's life. Dimond (1983) calls attention to the problem of balance between needing others and wanting to be self-sufficient.

Confusion About Social Support

Although there seems to be a lot of evidence that social support is helpful, the role of social support in mediating health is not clear. In fact, some researchers (Schaefer et al. 1981) did not find social support correlated with health. On the other hand, social support was correlated with depression and morale, which in my view could be a result of social network interactions. Lin, Woelfel and Light (1985) theorize that depression is reduced by strong ties. Hammer (1983) also supports the theory that strong ties, which she calls the core network, can affect susceptibility to illness. The confusing evidence about the effect of social support exists because of nonuniformity in concepts and measurements (Murawski 1978). Measures of social support are too diverse and have not been widely tested. Many researchers (including Brandt 1981; Norbeck 1981; Norbeck et al. 1981, 1983) have constructed instruments to measure social support, with emphasis on different variables. Starker (1986) is very critical of measures which are shaped to a particular researcher's conception of social support and thus cannot be easily

incorporated into other types of studies. The diversity of instruments has hampered a unified research effort on social support. Both researchers and health care workers usually ask patients about the amount of perceived support available, rather than observing supportive behavior. Researchers (Schaefer et al. 1981; Wortman 1984) have criticized this approach because the size of the social support network is seen as indicative of support. The existence of a social network tie does not mean that the tie will be supportive. In fact, any particular person may be a significant source of stress. The content of social interaction is the key to successful intervention in crisis situations (Porritt 1979). Quality in social relations may even vary within the same social relationship (Schaefer et al. 1981).

Suchman (1964) was an early example of a study which used properties of the social network (social structure) to assess impact of ethnicity and illness. This study consisted of interviews with a probability sample of 5,340 people in New York City. This concurs with (and predates) Granovetter's theory of weak tie access to information flow. The structural characteristics of the social ties in Suchman's study were density (how many of the people in someone's network knew each other), and intensity of relation (how much do they like each other). Suchman constructed an index from these and similar questions and

called it "social group cohesiveness." High levels of this cohesiveness resulted in lower knowledge about scientific health care. Not having knowledge about health care can lead to bad health outcomes. People can participate in health practices which are at best ineffective, and possibly harmful. These people were at a disadvantage because of the dense networks they were in. Although the results are not conclusive, it appears that structural properties of a person's network can make a difference in individual behavior. This research illustrates a major problem of research in the area of social support. The combination of the structural characteristics of density and intensity and other questions made it impossible to tell which part of the index was having the effect.

Another group of researchers proposed to investigate the relationship between social networks and coronary heart disease of Japanese men in Hawaii (Reed et al. 1983). They only found a borderline association between one of their social network scales and the incidence of heart disease. Thus, they concluded that there was no association between the two. However, these researchers combined questions about social networks into two indexes which they then used in the analyses. These indexes also contained individual variable components, such as marital status. It is no surprise that they did not find a social network effect on heart disease because they clumped individual variables into

scales which are supposed to measure something. This is often the case with research on social support. The researchers try to get some estimation of what they think social support is and then they apply that measure to their subjects. The results are confusing. More research needs to be done in this area with "uncontaminated" variables, that is, variables which measure one thing at a time.

The study of social support so far has been strewn with concepts but no consistent measure of what social support is. Confusion in studies of social support also exists because there is no clear separation between aspects of social support. Most studies treat social network, psychosocial assets and perceived social support as interchangeable (Schaefer et al. 1981). Sometimes the concept of social support is treated as if it were only the social network. But social support consists not only of the actual members in the network and the structural properties of that network, but also the psychological state of the individual and how that person can cope with their illness. Therefore, if research shows "social support" to be beneficial in some way, how do we know what aspect of social support may be responsible? Perhaps they are all responsible, but maybe only one aspect provides the benefit.

Thus, Wellman claims that researchers of social support have oversimplified the nature of social network ties. "Because we declare ahead of time that a set of ties

constitutes a 'support system,' we presume in advance precisely that which we want to leave open for study" (Wellman 1981:172). Most social support researchers assume all ties are supportive. Thus networks are categorized as either supportive or non-supportive. Wellman states that this constricts the data analysis. "A support system is a social network" (Wellman 1981:173) but researchers in social support tend to blur the individual ties into one measure of social support. Wellman claims that if social support researchers used social network analysis in the structural way, they could make more advances in their research because social network analysis looks at individual ties and their position and influence in the entire structure.

In addition, research in social support has been focused on attributes of the individuals involved and on the cognitive networks of who people say they could get support from others, rather than on actual observations of supportive behavior. This is another reason I think specific social network structures have not been shown more often to be causal in people's lives. Structuralists who concentrate on social network properties need to talk to functionalists who see in a vague way how social networks seem to help people in crisis. More empirical research on the actual behavior of social networks in stressful situations would be critical in determining exactly how the social network members might mediate health situations.

Precise and uniform measures of social networks should be applied to clinical situations so that a large body of uniform data can be collected.

My research was designed to look at the emergent properties of social networks themselves as independent variables which may or may not affect health outcomes. Thus if health outcomes are affected, the cause will be attributed to the structure of the social network itself and not some imprecise measure of "social support." Because of my belief that it is important to collect data using uniform measures, I am using instruments previously used with ESRD patients by Nissenson (1986) and Wolcott and Nissenson (1988). I also used social network instruments which I have experience with from previous research.

CHAPTER 4
METHODS

The Informants

For this study, I interviewed 53 ESRD patients (26 PD and 27 HD; 25 men and 28 women) who had been on their current dialysis treatment modality for six months or more. I had been told by nephrologists that it takes about six months to really adapt to the treatment. Patients with chronic psychosis, dementia, major hearing or vision impairment or wheelchair-bound patients were excluded from this study because their networks might be restricted as a result of these impairments.

There are variations in patient population by dialysis center, but in general about 72% of HD patients are black and 73% of PD patients are white (Tucker 1991; U.S. Department of Health and Human Services 1991). There are a variety of reasons for this disproportion. Whatever the cause of this difference in treatment modality, it was important to make sure I got an approximately equal sample of whites and blacks on each type of dialysis. Without an approximately equal sample, proper comparisons of races on different types of dialysis would not have been possible.

In order to obtain this disproportionate sample, I had to go to more than one dialysis center. Thus, the patients interviewed in this study were from 4 different dialysis centers. To protect the anonymity of the patients, I have used fictitious names for the dialysis centers and for the patients.

For the most part, HD patients were interviewed during their dialysis procedure. I talked to PD patients when they came to their particular dialysis center for check-ups.

Many independent variables may affect health outcomes. Some are informant characteristics: age, race, ethnicity, gender, income, occupation, whether or not the informant is currently employed, education, and marital status. People with less education and lower income, for example, are likely to show signs of inadequate nutrition and poor mental and physical health. When low-income, poorly educated people are black and female, the probability of poor nutrition increases (Winikoff 1983; Dimond 1983; Susser et al. 1983). To make sure I could check for socio-economic differences in dialysis populations, I asked informants things about themselves, including their age, income, medical status, etc., as mentioned above.

Some variables have an effect on health outcomes because they relate directly to kidney disease and how people cope with having ESRD (Nolph 1989; Czaczkes 1978). Some of these "illness variables" include: type of dialysis,

duration of illness (ESRD), and amount of time on current dialysis mode. I collected data on each informant about these variables.

I received permission, from physicians and the administration, to talk to ESRD patients at various dialysis centers. Most people were willing to talk to me. Only one patient refused the interview. Unfortunately, some patients who had already agreed to talk to me died before I could interview them. Some other patients changed dialysis modes or were transplanted prior to the interview time so I could not interview them.

The Network Instruments

Other independent variables which may affect health outcomes are the emergent properties of social networks. Some commonly described network properties include: network size, density, multiplexity, the percentage of strong vs. weak ties, the number of friends, relatives, acquaintances, and percentage of male vs. female network members. Networks of relations are elicited from people by the use of so-called "network generators." Each generator dredges up a different part of a person's whole social network.

Researchers have identified several different kinds of social networks which overlap. The largest network is the global "acquaintance network," consisting of everybody a person has ever met. Pool and Kochen (1978) developed and Freeman and Thompson (1987) improved a method for generating

this network. Freeman and Thompson took 305 randomly selected last names from the Orange County, California phone book. They presented informants with each last name and asked if the informants had ever known anyone with that last name. If the answer was "yes," the informant gave the first name, sex and relationship (friend, relative, or acquaintance) of that person. Informants were asked if they knew anyone else with that last name and they listed as many names as they wished. The number of names elicited for an informant was divided by 305 and then multiplied by the number of different last names in the Orange County, California, phone book. This number was a proxy for an informant's total network size. Bernard et al. (1990) did a similar study with a Florida phone book. However, they corrected the formula for computing total network size (Killworth et al. 1990). Brazill (1991) emphasized that the particular list which was presented to informants was instrumental in determining the number of names generated by that list. Therefore, since the ESRD patients I studied were all at dialysis centers in Florida, I used this phone book list for these ESRD patients and asked them questions about the Florida list.

The "social support" network is, by definition, contained in the acquaintance network. It consists of approximately 10-30 people who do things like help with child care and housework, provide transportation when needed

or a small loan. The social support network also contains those people with whom one socializes. McCallister and Fischer (1983) developed a method for eliciting the names of social support network members. This method was slightly modified by Bernard et al. (1990) and I asked those modified questions of the ESRD patients in my study. The questions used to elicit the social support network were

1. Who would take care of your house if you went out of town?
2. If you work outside of your home, who would you talk to about work decisions?
3. Who, if anyone, has helped with household tasks in the last three months?
4. With whom have you engaged in social activities in the last three months (such as going to movies, had over for dinner, etc.?)
5. Who do you talk to about hobbies?
6. Who is your "best friend?"
7. Who do you talk to about personal worries?
8. Who do you get advice from when making important decisions?
9. If you needed a large sum of money, who could you borrow it from?
10. Who are the adult members of your household, excluding you?
11. Who do you feel especially "close to?"

I also administered the Myers Resources and Social Supports Measure (MRSSM) to these ESRD patients (Myers 1981). The MRSSM is a network generator, but it also elicits details about the quantity and quality of network relations. The MRSSM is used to describe network characteristics such as 1) the number of important persons available for emotional and social support; 2) the proportion of these people who are friends, relatives, acquaintances; 3) the number of different ways an informant knows someone (multiplexity); and 4) the proportion of network members who know each other (network density). Informants also evaluated several kinds of social support and how important each was to them, and they indicated how satisfied they were with the amount of social support they received from each of their network members. I used this instrument because it had been used with ESRD patients by Nissenson et al. (1986) and I wanted to be able to compare my results with theirs.

I had some problems in coding the results from the MRSSM (Myers network generator). The instructions for coding call for using the raw counts of network density, multiplexity and reciprocity. This does not work well when you are comparing informants. Consider the case where an informant has five people in the network and all the alters know each other. Compare that to a network of ten alters and five of them know each other. If I coded it the way

Myers intended, the two informants would have an equal density of five. The standard definition of network density is the proportion of actual network members who know each other out of the total number of possible pairs of network members. To maintain this standard, I figured each informant's network density, multiplexity and reciprocity by percentages.

The way the Myers instrument measures multiplexity is somewhat puzzling. Multiplexity is the number of different roles or functions a person performs for a particular informant (Kapferer 1969). For example, someone could be a co-worker and a friend, or a relative and a neighbor. The Myers instrument assessed multiplexity by asking if the individual and the social network members participated in more than one activity or only one activity. The informant was to choose one of those categories. In my opinion, this is not a true measure of multiplexity. This was validated by unsolicited comments by several ESRD patients who said, "oh yes, I spend a lot of time with person X," so I engage in more than one activity with them. Or, "I don't see person X much, so I only engage in one activity with them." Thus, Myers measure of multiplexity really is a measure of amount of interaction with other network members and not a measure of true multiplexity.

The smallest network is the network of intimates. To get at this network, I asked the question used by Burt in

the General Social Survey of 1985 (Burt 1984). This question was "with whom have you discussed important matters in the last six months?" There are typically three to five members in one's intimate network.

A total list of network members, using all four social network generators, was compiled for each informant. Then I asked each informant certain questions about the people on their own list. The questions were designed to discover things about their relations with their network members. These questions were 1) how (specifically) do you know this person; 2) how long have you known them; 3) approximately how often do you communicate with them; 4)how "close" do you feel to this person? Informants were shown the following five-point scale to evaluate closeness between the informant and their network members: very close = 5; close = 4; not close, but friendly= 3; neutral = 2 and unfriendly = 1.

The Psychological Instruments

I administered several instruments to these informants which evaluated their mental status about being an ESRD patient. In this study, I considered mental status as one of the dependent variables, or health outcomes. Researchers usually use mental status as an independent variable which, either alone or with other variables, many cause something else. I am using mental status as a dependent variable because I am trying to discover if social network properties have an effect on physical or mental health outcomes.

The Cantril Self-Anchoring Scale (Cantril 1965) has been used to show how optimistically one thinks about the future (Nissenson 1986). This scale evaluates morale and life satisfaction. I showed the drawing of a 10-point "ladder" on which zero would indicate the worst possible life the person could imagine and ten would indicate the best possible life that the informant could imagine. Informants were asked to indicate a) where they were on the ladder right now, b) where they were five years ago and c) where they thought they would be five years in the future. Czaczkes & Kaplan De Nour (1978) found that most ESRD patients rated the past very high, the present high and the future extremely low. The pattern for healthy individuals is to rate the present higher than the past and the future even higher.

I also administered the Multidimensional Locus of Control instrument (MHLC). This instrument consists of 18 questions. The informant can choose one of 6 answers to each question: strongly disagree, disagree, slightly disagree, slightly agree, agree and strongly agree. As an example, one of the questions was: "If I become sick, I have the power to make myself well again." The (MHLC) instrument indicates how helpless someone feels in relation to life situations. The MHLC measures three things: 1) if the person feels in control of situations, 2) if the person feels that "powerful others" control situations and 3) if

chance events control situations. Higher scores on the second and third component of the MHLC indicate that a person feels that outside forces control illness. Research with ESRD patients has indicated that people who feel a strong sense of internal control are more likely to comply with dietary restrictions (Walliston & Walliston 1981).

The Profile of Mood States (POMS) is often used in evaluating the attitudes of people (Peterson et al. 1984; Nissenson et al. 1986; McNair 1992). It is a 65-question survey of recent emotions, including happiness, sadness, anxiety, etc. Informants were asked whether they had these emotions "0= not at all, 1 = a little, 2 = moderately, 3 = quite a bit, or 4 = extremely" during the past week.

The Physical Health Evaluators

I administered a 95-question medical questionnaire to the ESRD patients, asking about their current state of health. Questions included whether, in addition to ESRD, they had cancer, diabetes, hypertension, etc. I also asked their opinion of their health status, and whether they were satisfied with their life in general and their health status. I asked if they had been having problems with doing things around the house, with their personal relationships, sexual relations, vacations, etc. Part of this questionnaire consisted of a subscale which had yes/no answers about various aches and pains they had been having.

These questions included whether they had trouble going up and down stairs, had trouble walking, sleeping, etc. Answers to questions in the medical questionnaire are used here as indicators of health status.

Periodic blood chemistry tests also indicate the health status of these ESRD patients. The tests measure the levels of twelve blood solutes. Dietary compliance can be determined from serum phosphorous levels, for example. Adequacy of dialysis can be determined from the creatine or BUN (Blood/Urea/Nitrogen) levels. For each informant, I averaged the results of their last three blood tests.

An additional indicator of dietary and fluid compliance is relative weight gain. If a HD patient is not following fluid restrictions, the weight gain between dialysis treatments will be high. If a PD patient is not doing dialysis frequently enough, they may also become fluid-overloaded and their weight is high relative to their "dry weight" (normal weight for them without excess fluid). I asked doctors and nurses at the dialysis centers to evaluate their patients as to average weight gain and assign the patients to one of three categories: high, average and low weight gain.

Ethnographic Interviews

In addition to the extensive questionnaires I administered to these informants, I also talked to them for hours about what it is like to have ESRD and to be on their

type of dialysis. I asked questions about how they and their families and friends dealt with the illness and what kinds of problems ESRD had caused in their lives.

I have spent two years studying this subject and interviewing people. I have talked to the caregivers of these patients, including doctors, nurses, technicians, social workers, dieticians and transport drivers. In addition, I have talked to the patients' family members. I have gone to some patient homes and have witnessed network interactions. I have studied medical records and was able to go to weekly patient care meetings at some dialysis centers. I have talked to a lot of dialysis patients and I sat in patient waiting rooms and large group treatment rooms with my eyes and ears open. Although I talked to many more patients, I was able to conduct formal interviews with only 53 ESRD patients, 25 white and 28 black. These interviews took a minimum of four hours each and most of them took much longer, from eight to sixteen hours over a period of visits. I have spent over 350 hours interviewing dialysis patients themselves and another 300 hours doing all the other things I mentioned above. It took me a minimum of five hours to code each informant's quantitative and qualitative data.

Data Analysis

As a result of the semi-structured interviews and formal questionnaire instruments, I have 23 measured health

outcomes as dependent variables and 25 network variables as independent variables. In addition, I have 24 socio-demographic or informational variables which I also include as independent variables when appropriate. Not all variables are used in my analyses because some variables are part of other variables.

To analyze these data, I used the SAS statistical package. I tested all variables for normal distribution. I used t-tests for comparison of those variables which were normally distributed. For those not normally distributed, I used PROC NPAR1WAY which is a nonparametric comparison procedure in SAS. In this dissertation, when I discuss whether a difference is statistically significant or not, I have used the appropriate test according to assumptions of normality. When I am indicating different levels of significance, I will use the following symbolic notation: * for p-values of .05 level or below, ** for p-values .01 and below, and *** for p-values of .001 and below. The usual convention is to only indicate levels at .05 and .01. However, in order to illuminate fine distinctions in my data, I have included all three levels.

CHAPTER 5
LIVING WITH ESRD

The Dialysis Treatment

No one really wants to be on any type of dialysis but it is a way to stay alive when one's kidneys fail. Different types of dialysis are better for some people according to their lifestyles. Hemodialysis is done about three times a week but is very stressful on a person's physiology. However, it can be more or less forgotten about on non-dialysis days. Peritoneal dialysis, while done several times each day, does not tie a patient to a particular place for dialysis and is not as "harsh" on a person's body. Each type of dialysis has benefits to speak for it and factors which make it an unthinkable choice.

Hemodialysis

Hemodialysis is the type of dialysis treatment that is usually given in a group setting (i.e. a dialysis center). The patients from this study came from four different dialysis centers. The largest center was the Midtown Dialysis Center. This center has a large treatment room in which about 30 people can receive dialysis treatment at

once. The smallest center was the New Life Center which could dialyze about 12 people at once. The other two centers, the Maple Street Center and the Armstrong Center could dialyze about 16 to 20 people at once. All centers had isolation rooms where people with hepatitis or AIDS could be dialyzed.

During HD, the patient is seated in a lounge-type chair which can be adjusted from an upright position to a reclining one. The reclining position is very important because often a patient's blood pressure drops (called "bottoming out") and the patient's head must be immediately lowered to keep the patient from becoming unconscious. The chairs are lined up in rows, each chair with its own dialysis machine nearby. There are only a few feet between one patient's chair and machine and the next patient's area. The close proximity of dialysis chairs is necessary because one caregiver (nurse or technician) is responsible for several patients at once. Each caregiver is given a certain group of patients to monitor for that day. Caregivers rotate their areas periodically so that over a few weeks' time, they care for all the patients at a particular center. There are pre-dialysis machine preparations for which the caregiver is responsible. The caregiver must prepare particular medications (which will be given intravenously) and gather supplies which will be needed for each patient during dialysis.

The hemodialysis treatment room is like a small community. As with any community, there are certain ritual acts performed by all its community members. The patients are called from the waiting room to come to their particular dialysis machines and before they get started they weigh themselves or are weighed if they are unable to walk. They go get in their chairs and get their temperatures taken. Then a caregiver gets a standing and sitting blood pressure. The patients are asked what they weigh and then the caregiver figures out how much weight the machine must pull off the patient that day. This is figured by subtracting the patient's "dry weight" (their normal nonfluid overload weight) from their present weight. Some patients help caregivers by doing portions of the preparation themselves (i.e, taking their own temperature, getting some supplies together, washing their arms with antiseptic soap).

After the dialysis period is over, the dialysis needles are removed and the patients and/or caregivers must tightly hold a piece of gauze over the holes where the two needles were, until the bleeding stops. Waiting for the bleeding to stop sometimes takes a long time. While the patients are sitting in their chairs during this waiting period, caregivers take the dialysis machine partially apart and clean it in order to get it ready for the next patient. After bleeding has stopped, bandaids and extra gauze are taped over the patients' access site and the patients weigh

in and get their temperature and blood pressure taken again. These are compared to pre-dialysis values. Patients then go back to the waiting rooms to wait for their respective rides home.

Some patients have private transportation, but the majority of them ride in vans which are funded by Medicaid. There are problems with this transportation because vans are scheduled to come at times when the patients are supposed to be finished with dialysis. However, some patients bleed for a long time or are feeling particularly faint and are not allowed to leave until they are alright. The vans have to leave and then come back later for patients they missed. Patients are late getting home also because it can take a long time for the vans to deliver patients to their homes. In order to make sure everyone is on time for dialysis, sometimes patients are picked up so early at their homes by these vans that the patients sometimes arrive over an hour before their dialysis time. Between time spent on dialysis and time spent in transit, it would be practically impossible for a person on HD to be employed in a job on a dialysis day. Most patients would feel too tired and weak to work after dialysis anyway.

Patients come in "shifts" (two or three shifts a day, depending on the center), and so there is a great bustle of activity as the patients are started on dialysis during the initial period of the shift and also when patients are

"coming off" dialysis together. After patients are all connected to the machines, the dialysis centers quiet down while patients nap, watch television or read as their blood is pumped through the dialysis machines and back into their bodies. The pumping sound of the machines is a constant background noise to whatever else is occurring. At certain times during the dialysis cycle, the machine emits a beeping sound to alert the caregivers to do certain things or to warn caregivers of possible problems in the dialysis procedure (i.e. air or blood leaks). Often, many machines are beeping at once and a caregiver must attend to them all. If there is a crisis with one patient, the incessant beeping of the other machines continues until a caregiver can get to the other patients. This can be a problem for caregivers. A nurse, Ruth, described just such an experience.

> There is not enough time to care for patients adequately. Too many patients are started at the same time and you have to rush to get them on the machines on time. Then they all come to crisis at the same time towards the end of dialysis. As the blood gets cleaned, people feel worse and start to become nauseated and also "bottom out" on their blood pressure. At that point, we have to give them saline immediately or they may die. One day I was in isolation, alone with 6 patients who all began to bottom out at the same time. I was literally running from patient to patient, giving them saline and also something to throw up in, and yelling for help from the nurses in the other room. When you have to rush with many patients at once, there is a greater chance for error and for getting stuck with patient needles.

All caregivers try to be very careful, especially because of the risk of AIDS. Worrying about contracting AIDS is on Ruth's mind:

> Last year a nurse got accidentally stuck in the hand with a 15 gauge needle which was full of an AIDS patient's blood. The nurse started crying and I grabbed her hand and poured bleach and peroxide onto it and began pressing the wound, trying to get it to bleed. Another time last year, a "kidney" (the term for the 12-inch cylinder attached to the dialysis machine which filters the blood) exploded when I was standing right beside it and I was covered with blood from the waist up--hair, nose, mouth, eyes--everything. This was not a documented AIDS patient but you really never know if someone is HIV positive here. I am frightened of the risk of AIDS. I have read a lot on the subject and the risk of hemodialysis patients getting AIDS is 80% to 90%, because of the blood transfusions they have had to have. Patients who were IV drug users have an even worse risk. Our patients are not mandatorily tested for AIDS. If they go to another center for some reason, like a vacation, they have to have the test in order to get dialysis there and then the results are sent back to this hospital. And if the patient goes for a kidney transplant, they test for AIDS. Some of our patients have gone for a transplant and been disappointed to find out they were HIV positive and couldn't get a transplant. I was extremely upset last week to come in and find blood all over the side of one of the dialysis machines. That is very dangerous and means that someone didn't properly clean up after a patient. They won't give us adequate protection against contracting AIDS or hepatitis. We asked for face shields and goggles and were refused the face shields by the administration who thought they weren't needed. But I wear glasses and I can't use goggles over glasses. I have to have a face shield.

All dialysis centers are set up similarly with dialysis chairs in rows around the room and one or more caregiver stations nearby. But they are somewhat different in what patients are allowed to do. Some centers allow patients to bring food into the treatment room and some do not. Reasons

for not allowing food include cleanliness problems and the fact that caregivers often have to clean up after patients. Several patients told me that eating while on dialysis prevents nausea at the end of the treatment. The New Life and Armstrong centers did not have televisions in their treatment rooms, but the Maple Street and Midtown centers did. The televisions were mounted on the treatment room walls, so that each patient could see at least one of them. Some disagreements between patients arose about what to watch, but in general they were all tuned to the same thing: game shows in the morning and soap operas in the afternoons. If one was not addicted to soap operas upon first beginning dialysis treatments, it would not be long until one was. Caregivers and patients would sometimes discuss the plot and activities of such shows.

Sometimes it seems as if all the patients in the treatment room are like one family. Heather, an HD patient, described this feeling:

> There is a family atmosphere in dialysis. We are one big family. We talk in the lobby. In the other lobby, people were closer because they had to sit closer together. I have gone to see some good friends who were also on dialysis even though they were black. If somebody says they want something, I try to get it for them--like candy or home canned foods. I have family to get things for me, but some of them don't. They are here one day and might not be the next so that's why I like to do things for them. I knew everyone on the dialysis shift I was on before and then I changed days. The old group (patients on her old shift) got together and sent someone to check on me and make sure I was ok.

If someone does not come in for dialysis anymore, there is a strong possibility that they have died.

In the dialysis centers, everyone seems to know one another. Even if they do not know last names, they know each other's first name. This is because the caregivers usually call the patients by their first names. When someone is having trouble, all the patients watch carefully as to the outcome, or help each other if they can (although they cannot get up from their chairs). Because they are all getting treatment together in one room, they hear comments said to patients by staff and to fellow patients. Privacy is practically impossible. Patients are sometimes seen in various situations where they are not completely dressed. It is almost as if in this situation of group medical treatment, there is no need or desire for modesty.

One day I saw an elderly woman in isolation take a complete bath (including her hair and genitals) with a bottle of rubbing alcohol and a washcloth. The isolation ward had four men and another woman in it. She was fairly modest and washed herself underneath a sheet while sitting in her dialysis chair, but at several times, body parts which were usually covered were exposed. At one point she stood up and put on her underwear in full view of everybody. She seemed to be oblivious to the other people in the room. Dr. Johnson explained this. He said,

> That was just Cleo. She does that every time on dialysis. What you didn't see was that before dialysis

> she coats her entire body, including the hair on her head, with cocoa butter. She has a terrible time with itching on hemodialysis. She was unable to find any relief for it until she found the cocoa butter. When she is itching so terribly, she feels as if there are worms crawling out of her skin. Anyway, after dialysis she has to get the cocoa butter off and that's why the alcohol bath. She is blind but she knew there were others in the room. But she does it no matter who is watching. I've seen other strange sights in dialysis. One day I walked into the dialysis room and there was Luther, sitting in his dialysis chair, completely naked from the waist down. Apparently he had gotten warm and just undressed.

In a group treatment situation, such as hemodialysis, individuality is submerged. It is almost as if the group is one entity during that treatment period. One day I was particularly aware of patients' collective reaction as they heard the piercing screams of Jordan, a six-year old HD patient, when the caregivers inserted the 1.5 inch HD needles in his leg. The veins in his arms are too small for the large HD needles. Jordan had been on PD all his life but was no longer able to have that kind of dialysis. It takes several nurses to hold Jordan down while they insert the needles. These needles can be very painful for adults but it is much worse for a child. During the process of getting Jordan hooked up to the machine, the whole room is tense because they know well what he is going through and they all feel bad for him.

In spite of everything going on at dialysis centers, many patients sleep through their dialysis treatments. Frank, a hemodialysis patient, said:

> I can't sleep at night. I get only about two hours of sleep. After I get home from dialysis, I eat something and then sleep for about two hours. On dialysis I get tired of sitting. I sometimes get sick to my stomach and have cramping. It is also painful sometimes when they stick me. Being on dialysis makes me hungry. If you have an empty stomach when you are on the machine, it makes you sick. Looking at the four walls three times a week, I get tired of it. I feel like time ain't moving. I get restless. I want to get away from the monster (the HD machine).

Often Frank falls asleep almost instantly when he goes on dialysis. One nurse, Betsy, said that Frank even "has fallen asleep during the needle stick and putting him on dialysis." Perhaps he is so used to sleeping on dialysis that he can not sleep at night. Patients often report sleeping after they get home from dialysis. The dialysis procedure drains them and makes them very tired. However, all this daytime sleeping could contribute to the reasons why they sleep badly at night. Some HD patients get about five hours sleep during the day (three during HD and about two when they get home from treatment).

In all, HD is usually an exhausting, time consuming experience. Patients find various ways to spend their time but no matter what they do, no one likes being there. Going to sleep is a way for many patients to get through the treatment. Leonard, an older gentleman who had been very productive in his life said,

> Dialysis really affects my life. It's boring and I don't like the needlesticks. Some people are better than others in doing it (the needle punctures). I feel drained of strength after dialysis. It's time-consuming and I feel useless. I used to be busy all

> the time. Now I can't stand up or work for more than 10 minutes at a time. I don't have the strength for jobs around the house. I can't do woodworking or fishing anymore. I'm planning on getting on PD at night. My wife doesn't want me to but she has been very good through all this.

As bad as HD seems now, I talked to a caregiver, Helen, who has been around dialysis since 1968, when her husband had to have dialysis. She had to train to do machine dialysis at home and she says that is why she later became a caregiver after his death. Helen talked about the improvements in dialysis since 1968.

> Back then the patient had to sit connected to the machine for ten straight hours three times a week. The filtering membrane was made of sausage casings and you had to partially construct the filtering device yourself. The tubing installed in a patient's arm was artificial, no natural substances, and it clotted all the time which required frequent surgery to clean it out or replace it.

Helen said she was "burned out." She can no longer work with patients. She is a supervisor of technicians and does managerial work, but has no caregiving contact with patients anymore.

Peritoneal Dialysis

This type of dialysis is usually done alone, or only with close family members because it involves partial undressing. The procedure for PD has been described in an earlier chapter. However, in general, recall that it involves the infusion of filtering liquid into the abdomen via an abdominal catheter. The conditions during PD must be

absolutely sterile to avoid the chance of getting peritonitis. During the PD procedure, the catheter is only open to the air for a few seconds, or however long it takes to make the connection. All patients are supposed to wear a mask during this procedure, although some do not. Instead, they hold their breath when they are making the connection.

Laura, a successful PD patient, told how to do CAPD:

> Get everything out you need. Wash your hands up to the elbows. Put betadine (an antiseptic) on the (catheter) tubing and leave it on for 5 minutes. Use paper towels to dry your hands and even use a paper towel to turn the water off. Don't breathe toward the tubing. Then clamp off the bag and take the top off the plastic tubing. Let the fluid drain out of your body into the attached bag. Just lay the bag on the floor. It takes about 15 minutes for the dialysate to come out. It feels like a vacuum when you are through emptying out the dialysate. It hurts a little when you are empty. Then you put in a new bag. (The new bag is hung or held higher than the patient's head and the liquid allowed to inflow. This also takes about 15 minutes.) I know what to do if there is an infection. If the dialysate is cloudy, I do 3 quick flushes with a 1.5 (% glucose solution) and the last one you leave in and put the medicine in. CAPD is just common sense. You have to know how you feel. Your lifestyle has a lot to do with whether you can handle dialysis. A protected woman couldn't do it. People with no self-confidence wouldn't be able to do CAPD. People call the nurses when they don't know what to do. I am living with dialysis, instead of being on dialysis. I rule dialysis, it doesn't rule me. I see dialysis as a job. The only thing to worry about is when to do the exchanges. I was on hemo (hemodialysis) and I hated it. I felt weak and sick after hemo. For the first 3 months someone drove me to dialysis but after that I drove myself even though I felt sick afterwards. On the machine I would have anxiety attacks. My blood pressure was too low. I had to sit in the chair three hours every other day and dreaded it. Sunday and Monday I didn't have to go but I was still sick. My lifestyle on hemo was different. I was always tired and always dreaded the three hours of sitting there. I was happy to start CAPD. It gets better every day. I know I have to do the exchanges and I make time for it.

> I know by the way I feel what I need to do. In the morning I check for edema, and take my blood pressure. If I have edema, I do three 2.5% bags and one 1.5% bag. If there is no edema, I do a 2.5, a 1.5, a 2.5 and sleep with a 1.5. I have no problems with CAPD. It's a question of acceptance of what you have to do. The catheter is part of me now. CAPD is an attitude as well as anything else. While doing CAPD I read or write letters.

At first, patients are very careful about how to do the PD procedure. But as time goes by, they usually become less strict with themselves about where and when to do PD. Some patients do it in public restrooms, offices or in their cars. Some patients admitted that they even allow themselves to skip PD treatments. For example if they can not do them at all during the day, they will do all of them in the evening. As long as nothing terrible happens to them (i.e., they do not get peritonitis, or severe fluid overloading) they feel they can get by with it. One of the nurses, Janean, commented on patient lack of care in doing CAPD. She was talking about a particular patient who "doesn't wear a mask or wash his hands. And he just dropped his bag (CAPD outflow bag) right in front of my desk, which made me very angry but I didn't yell at him."

Patients can get peritonitis if they do not follow proper sterile PD procedures. Jason said that having peritonitis is "like being shot in the stomach." Besides being extremely painful, it is also very dangerous and if antibiotics are not administered soon enough, peritonitis can lead to death.

Patients on PD have to have a place for storage of bags and other supplies which are delivered to their homes. One PD patient, Wilma, talked about storage of supplies:

> I always have on hand at least five bags of 4.25 dialysis fluid, five bags of 2.5 and five bags of 1.5. I have 4 boxes of y-sets and a UVX (a germicidal exchange device). The whole side of one wall is covered with boxes and every month they bring more, with extra in case of a disaster. I receive about 21-25 boxes of solution per month and five boxes of y-sets, a case of 4x4 gauze pads, iodine, peroxide, tape, needles, syringes. I have to sterilize everything, including the top of medicine bottles and the needles used to administer medicine. I have to know how many cc's of medicine to use for an infection. At first when I got on CAPD, I couldn't sit or stand and my catheter was hard to get used to. After about 6 months I felt comfortable with the catheter and even show it to people who ask. I tried to work for awhile on peritoneal dialysis but had trouble walking and had to quit. I had three peritoneal catheters because the first two got infected. I was on hemo for four years and CAPD for five years. I got stuck wrong by the nurses and got aneurysms in both arms. I hated the hours on hemodialysis and hated the needles. I got sick, weak and had no energy when I came off the machine. I got 'low blood' from the dialysis. I had trouble with my bones because of hemo. As a result I have had broken bones and was even paralyzed for 6 months. They took out my parathyroid glands to try to help prevent more bone damage.

Julie let me see her do two complete PD exchanges. She is a PD patient who has great insight into the situation of ESRD patients, perhaps because she has been one so long and herself been on different types of dialysis. She has even had transplants. During the procedure, I wore a mask, as did she. Her abdomen was a mass of scars, and so were her arms, because of different access sites for HD. Julie has had 12 major surgeries and has been so sick she was down to

68 pounds and her muscles would not function. She told me about one of the last surgeries she had,

> They had given me up for dead on the last surgery. I had been taking heparin (an anticoagulant necessary for HD). I began bleeding internally in the diaphragm area. By the time the ambulance got me to the hospital, I had lost 400 cubic centimeters of blood, which was all just sitting inside my chest and making it difficult to breathe. They didn't think I could survive another surgery; They thought I was too weak. I could hear them talking about me as if I were already dead. But in came my doctor and I heard him say 'prepare her for surgery. She has had 10 surgeries with me. She's a fighter. She will make it.' The nurses didn't want to do it but they did what he said and I made it.

The Choice of Dialysis

Often, other people besides the patient make the decision as to type of dialysis. Physicians have opinions about preferred therapies. They can steer their patients to preferred options by "nuance and optimistic shading" (Friedman 1984) or by just not informing patients of all the options. Several patients in this study were not told of PD when they first were diagnosed with ESRD. But when they found out about it they chose PD.

There are many reasons for choosing one dialysis therapy over another. The social network (spouse, family and friends) can have a big influence on options for dialysis. Family members may wish to have more time with the patient, or more family freedom to travel, and thus desire the patient to choose a form of home-dialysis (i.e. CAPD). Some people do not want to dialyze in their homes

because they do not want family members to see them. The family becomes more acutely aware of the dialysis procedure when it occurs at home and this can increase family stress. Families sometimes fear that there will be a medical emergency while the patient is on dialysis and so in-center hemodialysis is preferred. In addition, some spouses find the implanted catheter required for peritoneal dialysis physically repulsive and so they also prefer the patient to choose HD. Another reason for choosing in-center hemodialysis is that PD requires physical space for equipment and supplies, and a sterile area for the dialysis procedure to be performed. Some families do not have the facilities for this. People who do not have a stable place to live will also have to overcome difficulties to have PD.

Some patients in my study chose their type of dialysis based on misconceptions and folklore. Shawn said,

> On hemo I get low blood and feel dizzy sometimes. I get cold on dialysis. The worst thing is that it takes your free time away and you are tied down. No one told me about peritoneal dialysis. But anyway I'm afraid of not doing it like it should be done. I'm afraid I probably couldn't adapt to it, couldn't adapt to taking care of myself. I'm too dependent on these machines.

Frank said about PD, "pero (PD) is dangerous. You get infected. Gangrene set in." Sam said,

> I'm not interested in PD because it would be such a hassle, doing it five or six times a day. I did hemo at home for seven months with my wife's help. We trained for seven weeks and my wife was sweating bullets. I did the needles myself. She feels better now that I'm doing hemo in the center.

Patrick decided upon PD because,

> I talked to people who were on hemo and they seemed like the strength was drained out of them. I would see people coming off hemo and feeling bad and I knew I didn't want to be that way.

Shannon was not interested in PD because "PD is too much trouble. Besides, I sleep wild and I thought I might disconnect the machine." Cindy said, "I don't like the idea of having something in my stomach."

Sabrina, an HD patient said,

> I would never take peritoneal. With hemo, at least you know what's going on. You have more control over your body with hemo. (The ironic thing is that actually she would have more control over her body with PD because her diet and time schedule would be less restricted.) I had a patient friend on CAPD die recently. I'm tired of my friends dying on me, so it's better not to get close to anybody. With CAPD you are a long way away and something could go wrong at home. You have a better chance on hemo of cleaning your blood. I am bothered by the way my arms look, though. With hemo my arms look like a dope addict. People ask me about it and I'm sensitive about it. I do have to watch out for blood poisoning.

Mike, a young HD patient, said,

> Oh no! Strictly hemo, no pero (PD). I don't want nothing sticking out of my body. My nerves ain't up to that. You have to be stuck all the time with pero. I also wouldn't want the catheter because of the possibility of scaring away dates. I don't tell anyone that I have kidney disease unless they ask. The nurses tried to get me to change to pero, but I've been here too long. I don't go to clubs and bars anymore because you always see the same people doing the same thing and it's monotonous. (But when I asked him if HD was monotonous he said) No, this is life, it's not monotonous. I love hemodialysis--no peritoneal. I've heard of complications on CAPD with regard to infections and having to have surgery to replace infected catheters. Besides peritoneal patients have to be on their bag four to five times a day and when I'm through with this, I'm through until the next dialysis. Besides, you can't have any cats, dogs, or birds and be on CAPD. And dust is a problem. Everybody has dust. Dust is germs. The hole in my arm

> needed for HD is small so it's not going to get infected, like the catheter for CAPD might.

Mike has a graft, rather than a fistula. He is aware of the "rush" inside his arm (on the inside of his elbow). If he ever can not feel that, he knows something is wrong with his circulation. The arm of a dialysis patient with the graft (or fistula) is "off limits" to medical personnel. They can not use it to get blood pressure, blood tests, etc. or they might damage the internal connection and would have to have surgery because they would be unable to dialyze. Patients have to be careful not to lay on that arm or put it in a position where the circulation might be cut off.

Jacob, another young HD patient, said, "I wouldn't want pero because it's the same thing as hemo only you just have the machine at home." Frank believes "you just do PD whenever you feel bad." Both of these are misconceptions but are believed by the people who told them to me.

April is on PD now but had to be on HD for about 3 months initially.

> Peritoneal is heaven compared to that other (HD). My blood pressure dropped each time. My husband had to assist me to the car. I was exhausted until the next day. I was nauseated and dizzy and felt like I was going to pass out. The minute they gave me the saline I felt better. They were trying to pull too much fluid. There was a machine malfunction and a particular machine pulled too much. I watch my drinking. My sister died after just coming off hemodialysis. Hemo helped me but I was afraid (because of her sister's death). I like CAPD better. As a diabetic I can put my shots in the bag instead of in my body directly. An exchange takes me about 20 minutes. At first CAPD was uncomfortable because I felt like I was 6 months

> pregnant and felt too full. But in general I feel better with CAPD, but you have to be very careful. I have a lot of freedom with CAPD. I have a room at home with my dialysis stuff in it. I do my exchanges there. I do CAPD four times a day and my husband would rather have me on that method than hemo, or even the cycler at night. I do have some problems with CAPD though. I can't wear form-fitting clothes. I even have some clothes that I can't wear any more.

Many patients are adamant about staying on their dialysis type. I was impressed by how vehemently the HD patients were against going on PD and how much more freedom they thought they had than PD patients did. CAPD patients are just the opposite, and just as vehement about it, and some of them said they would rather die than go back on hemo. Jason, a PD patient, said,

> Hemo is a roller coaster ride. Going on hemo would scare the living hell out of me. If I had to choose hemo or death, I don't know which I'd choose.

Tim has never been on hemo and would never try it.

> I won't go hemo. I don't ever hope to. I'll die first. I won't let 'em put a shunt in my arm. Doctors and nurses take better care of you if you try to help yourself. CCPD is the only way to go. There is no pain on CCPD. I can look at my watch fit and weight gain in my hands and feet and know how much weight to pull off at night. You need to know your own body. I can feel if my phosphorus or potassium is high and will adjust my diet accordingly.

One female patient said, "if I were forced to live the remainder of my life on hemodialysis, I'm not sure I would choose to live. I don't think my doctor realizes this."

Scott echoed these feelings,

> If they told me I would have to go back on hemo, I would take my gun and go out and shoot myself. I love CAPD. It's simple; a child could do it. I debated about it for 5 years. There was a fellow CAPD patient who had CAPD and I used to call him about it and would always talk about my problems to him. I was on hemo for 4 years and hated it. It gets old. I felt trapped in hemo. You walk in, physically strong and four hours later you feel drained. People can't say they don't want to come to hemo; they have to. People know about CAPD but a lot don't believe in it. It's not guaranteed it will work and they are scared of this (he pointed to his catheter). It's a mind thing. I hated hemo and would rather die than go on it again. I can't sit in a chair for four hours. Hemo drained me and made me tired. I feel that CAPD is better anyway because my body is in more equilibrium.

Another patient who has been on HD and is now on PD said,

> On hemo, I was dizzy and had to sit for 30 minutes after treatment. I felt bad afterwards and I have seen others feel bad. Hemo stinks. People on hemo have grotesque arms and they have to add shunts from time to time. It ties you down. Hemo's like living death as far as I'm concerned.

Living with Death

It has often been said that dialysis is "living on borrowed time" and that dialysis patients are alive past the time that they were meant to be alive. Thoughts of death and death itself is a constant reminder to all dialysis patients. Often people fear going to the doctor because they think they will be diagnosed with a terrible disease. Dr. Johnson told me that, "my black patients fear dialysis and don't want to start it until absolutely necessary

because they all know someone who has died while on dialysis."

Eric's sister died on dialysis a few years ago.

> It was hard for me to adjust to dialysis. It took me about 2 years to get out of the denial stage. I assumed I would die so I didn't want dialysis. I had a lot of anger. I had good support, but wanted to be by himself.

Mike's aunt died several years ago because she bled to death after a dialysis treatment.

> My aunt went home after dialysis and started bleeding from the access site in her arm. She tried to go to a neighbor's house for help (since she didn't have a phone) and was found the next day in a pool of her own blood.

Bleeding to death is a clear possibility for HD patients. Recall that patients have to sit in the dialysis chair until their access site clots off and they are no longer bleeding. One day I was talking with a woman who usually bled a lot after she got off the machine. She only has to be on the machine two hours but she said she sometimes has to sit there for another two hours afterwards to make sure her arm stops bleeding. This day the nurse thought her arm had stopped bleeding and had put a bandaid on her arm. All of a sudden, blood started pouring from the bandaid, just like a stream of water from a faucet. It was quite unnerving. The patient called to a nurse who came over quickly and put a pad and a clamp on her arm again to stop the flow of blood. It would be very easy for someone to bleed to death if they were not supervised.

Casey told me about someone who had a heart attack on the dialysis machine last year, at the end of the room from where he sat. "It upset everybody in that room and they had to end up taking some of them off their machines, because of blood pressure and heart problems" in response to the death.

Mike told me several stories about dialysis patients who died.

> When Fred came in he complained of being cold. He put a blanket over himself, including his head, and no one could see him. He died under the blanket of a heart attack. Burt wanted to leave the center after dialysis before the nurses could get his blood pressure down. He went home and died. Jack took responsibility for taking himself off the dialysis machine after only one or two hour sessions, instead of the minimum required three hours. He was going crazy on the machine and felt trapped. He eventually died because of not enough dialysis.

The whole dialysis center was talking one day about a woman whose family seemed to contribute to her death. She had been having seizures and her family knew about it and yet they let her drive alone to and from dialysis. She died recently because she had a seizure in the car on the way home after dialysis and her car ran into a tree. Dr. Johnson said that "if the staff had known about the seizures, they would not have let her drive."

During my study, I was in a dialysis treatment room while someone was dying on dialysis. It was a heart wrenching experience for me. But I am sure it was much worse for the patients in that room with ESRD who wondered if that kind of death would happen to them someday. I was

interviewing the patient directly beside the dying woman. The caregivers had put portable screens around her because she was "having a bad time" as Dillon told me. As I interviewed Dillon, I could hear moaning coming from behind the screen. The dialysis chairs are about five feet apart. I asked Dillon if it was depressing to see fellow patients like that who were having trouble. He said, "I've seen a lot of people having trouble during the time I've been on dialysis and I'm used to it."

People kept going behind the screen and it was increasingly apparent that the woman was going to die. In fact one of the nurses indicated that to a fellow technician. The caregivers seemed concerned about what would happen if she died in front of the rest of the patients. There was a caregiver with the woman all the time holding her hand. Although we couldn't really see the dying woman, we could hear her. Her breathing was labored and all the patients nearby could hear a rattling sound as she breathed. Fortunately for the rest of the patients she did not die there but on the way back to the nursing home. But everyone in that dialysis room knew exactly what was happening and I am sure that thought weighed on their minds for a long time. It did on mine.

Thoughts of death are common with dialysis patients. Jason said,

> I never thought about death before. I do now. I want to accomplish things, just in case I don't live to

> finish it. I never used to be afraid of anything. I would stand up to anybody, no matter what weapon they had. I would do anything--walk high up on construction sites, climb anything, and not worry about dying. Now you feel like you are going to die and will definitely have a shorter life. You go into a death syndrome. You are buying time with dialysis. Anytime you can't do things you planned to do, it gives you a bitter taste. You feel you have to prove something. You feel like a freak. People look and turn, like a burn victim. It's always there.

Valarie talked one day about the death of a fellow CAPD patient. She said, "I'm not overly concerned with dying, but I have told my daughter that it could happen so she will be prepared. But I don't live every day in fear that I will die that day."

Patients do not really expect that they will die any minute. Like the rest of us, as long as they are feeling alright, they think things will go on as they are. Dietary indiscretions are not considered particularly harmful if they do not cause an immediate adverse reaction. One patient, Amy, talked about life as an ESRD patient and how she deals with it.

> My family is just glad I'm ok. Whatever I decide is ok with them. They take special care of me and keep me from overexerting. I am less active than I was before (pre-ESRD). I do mostly the same things but just not as much as before. In the beginning I was depressed. It got me down but I had to deal with it. It took me two years to get a good attitude. The fluid restrictions don't bother me. I don't go exactly by the diet. I'm sicker when I'm on the diet. When I get short of breath or I feel sluggish that is a sign that I've been eating something bad. I make my own decisions about what to eat and how to take care of myself. Nobody can do it but me. It's my body and I want to live.

Unfortunately, she did not live. A couple of weeks later I came back to administer the medical questionnaire to her and found out she died due to "complications of surgery." She had completed all parts of the formal interview except the medical questionnaire; therefore, her data were included as one of the 53 informants in this study. Of those 53 informants, four are now deceased. Five other informants, whom I had talked to minimally, are not included among the 53 informants, and are also deceased. Three of the 53 informants received transplants since being interviewed. One of those transplant patients is now dead. Because of the nature of ESRD and transplants, these figures could change at any time.

Quality of Life

Many researchers try to improve the ESRD patient's "quality of life." Quality of life has three dimensions: psychological, social and physical health. Good health outcomes means good quality of life. My research has been involved with trying to see if there is a network effect on quality of life.

Wolcott and Nissenson (1988) found PD patients to have a significantly higher quality of life than did HD patients. PD patients had less physical symptoms and less reported life stressors than HD patients did and were more active in their communities. The PD patients also reported having a

better relationship with physicians. This makes sense because physicians have to take more time and interest in CAPD patients due to patient involvement in dialysis. The superiority of CAPD with regard to the psychosocial dimension of "quality of life" were consistent with the National Kidney Dialysis and Transplant Study also (Evans, et al. 1985).

Bremer et al. (1989) found that CAPD and in-center HD were judged about equal in "quality of life" as measured both subjectively and objectively. A study on perceived stresses of dialysis found HD and PD patients named similar physical complaints and similar numbers of stressors, including fatigue, sleep disturbances, back pain, decreased sex drive, etc. (Fuchs 1988). The PD patients in my study found sexual problems and trouble with social life most problematic and they claimed to have more problems with these life situations than HD patients did.

Thus, there have been many studies on the differences between HD and PD patients. There are conflicting results as to which is really better. In the end, it seems to still be an individual decision, based on many factors, including the influence of social network members.

Feeling Nonhuman

Both HD and PD patients have problems with negative self-image. Part of this stems from the loss of kidney

function which sometimes results in the cessation of urination. Although people do not normally feel concern over everyday bodily functions, these functions can become important if one is unable to do them. Somehow this loss of function reduces one's sense of being human. In addition, HD patients fear losing part of themselves by becoming part of the dialysis machine. CAPD patients feel less human and less attractive because of the implanted catheter and attached dialysis bag. These feelings can also contribute to feeling less masculine or feminine. This can have a devastating effect on pre-dialysis dominant males, because of the role reversal caused by the male having to be in a perpetually dependent, sick role (Burton et al. 1989).

Some of the patients I interviewed expressed feelings of nonhumanity. Jason said, "you feel like a freak, not like other normal human beings. When you talk about humans, you leave yourself out." Brandon also felt this way.

> When you're on dialysis, you don't fit in. You feel less human. The machine comes to be a part of you. I found out that if I come to dialysis I do good, if I don't come, I don't do good.

Dr. Edwards described dialysis thus: "the dialysis world is not normal; it is a bionic lifestyle." The act of having HD can be a dehumanizing experience. People depend on the machine to control their diet and fluid indiscretions. They become a part of the HD machine for several hours a week and have to depend on it for survival. Casey says,

> I feel peppy unless they drain me out when they turn up the machine too much (when too much fluid is pulled out of the body.) On hemo, you feel extremely tired and weak and you usually don't get straightened out until the next day. They can put the fluid back in by putting in saline solution, but I would like it to be natural, and not like that. I depend on the hemo machine to get my pressure down. I can't take blood pressure medicines because they make it come down too fast.

Even PD patients have to depend on something artificial to live. They are no longer as they were before ESRD and must find an artificial way to rid themselves of impurities in their blood. This process which used to be done automatically by their bodies must now be a conscious effort. People without ESRD take the process of urination for granted; some may even consider it a bother. Jacob is a current HD patient who previously had a transplant. His new kidney worked for a while but then it soon failed before he even got home from the hospital. Jacob told me,

> At first my new kidney was working fine. But I wasn't used to having to get up to go to the bathroom and so I wet the bed. I got very excited about wetting the bed. Can you imagine, a grown man being excited about wetting the bed? But I cried when they told me I lost the new kidney and I got very depressed about it.

People on dialysis live complicated lives. No matter which type of dialysis they choose, dialysis patients have to make time for their treatments. These treatments interrupt normal life. Diet and fluid restrictions are a problem to many patients. Paying attention to what they eat and drink can make a difference in the quality of life of dialysis patients. But Paul, a PD patient, says it "takes

me two hours to go grocery shopping because I have to read all the labels." Sometimes it is just too exhausting to keep track of everything. Getting enough dialysis treatments can also make patients feel better. But people tire of the dialysis treatments and for one reason or another they either miss treatments at their dialysis centers, or do not do their PD exchanges. Their fellow patients die and they wonder if they will be next. Dialysis patients know that their lives have been extended by artificial means and it bothers some of them. Ruth is a caretaker who seems to understand how hard life can be for these patients. She said,

> I have a lot of compassion for these patients. I know that most of them will not be around long and I try to make their time as enjoyable as possible. I used to wonder why the patients really celebrated holidays, even little holidays like Labor Day and Memorial Day. Then I realized that they never know if they will have another holiday to celebrate. I understand when they get off their diet or even didn't show up for dialysis. I know they sometimes got depressed over their lives and have to splurge occasionally.

Dr. Johnson said, "the desire to be normal causes a lot of patients to skip their dialysis treatments or not take their medication." Kidney patients do want to be normal. They do not want people to talk to them as a "kidney patient." They want to talk about normal things. Julie has a very good friend who doesn't treat her like she is sick.

> I can really can talk to her about anything. The friendship is so good because she assumes that I can do things. She doesn't tag me as a kidney patient. There

> are things you can't talk about to a husband, just your best friend.

Mike's philosophy is that "you can't get depressed about kidney disease or you will make yourself sick. Life's too short to be anxious about your health." Rick would rather be normal but he says,

> I'm a realist, what choice do I have? I believe in God and that there is a reason for everything. But once every week or two I ask, 'why me, God?' When I'm dialyzing I'm reminded of my restrictions and I get very upset.

Julie thinks that mental attitude is important.

> You can make it worse if you dwell on it. You have to deal with survival and make trade-offs. I can't always do everything I need to do. I feel that I have my life under control but sometimes I have to choose between two activities that both need to be done. Sometimes I even do things like take a walk or feed the birds, which don't need to be done but it helps me get control of things in my mind. Then after I do that I can come back and do what I need to do. So, in order to know what it's OK to let go, you have to know what's important so that you have knowledge and control. My doctors have helped me with that. But I don't always tell everyone about my CAPD. I would rather talk to them about normal things, not my disease.

Mike says, "I don't tell anyone that I have kidney disease unless they ask." Tim does not tell others either "unless they ask me and then I will tell anybody that wants to know. However, most people you meet are ignorant of ESRD." Brandon said, "I don't want my friends to know where I go on dialysis days. They just know I can't hoop (play basketball) on those days." Dillon still is able to be active with his friends in games; however,

> when we play ball I put a pad around my access site. I try not to tell anybody that I am on dialysis. I have explained it to my close friends only. If people find out you have a weakness on you, they use it.

This is the real problem. Many dialysis patients feel that they are not normal; they are somehow inferior because of their medical condition. But they do want to be normal and may sometimes ignore their condition and not follow their diet and dialysis regimens in order to pretend, even for a bit, that they are just like everyone else again.

Julie has been on dialysis for many years and has some ideas about what she thinks is important for "sane survival with kidney disease."

> You need: 1) a good mental attitude; 2) friends; 3) someone living in the same house who can give emotional and physical support to help you physically do things when you can't; 4) someone outside of the house like a best friend who can give emotional support and possibly physical support; 5) a holistic doctor who treats the patient as a whole, not one who just treats the kidney; and 6) an interest or a hobby to get you motivated and up and out of the house.

The items on this list would be of value to anyone, but would be particularly important to someone with a chronic disease like ESRD. Life on dialysis is tough and dialysis patients make the best of it that they can. Sometimes they have to choose between doing what they are supposed to do medically and what would be best for them emotionally. The members of a patient's social network can help guide those choices and influence the quality of life of ESRD patients.

CHAPTER 6
RESULTS

Description of the Patients

During the course of this research, I talked to quite a number of dialysis patients. I administered many different types of questionnaires to them and I also just listened to them talk about what it was like to have ESRD and to be on dialysis. Table 1 shows the distribution of the overall sample. I was able to conduct the formal interview with 53 patients, 26 on peritoneal dialysis and 27 on hemodialysis, 25 males and 28 females. Because of the disproportionate number of blacks on HD and whites on PD, I wanted to get an approximately equal number of both races on each type of dialysis. This turned out to be extremely difficult. I interviewed patients at 4 different dialysis centers in the northeast Florida area and was still not able to get a completely equal sample. I did a Chi-Square test on the frequencies of race, sex and type of dialysis in my sample and found no significant differences. I conducted formal interviews with 12 blacks on PD and 14 whites on PD, 16 blacks on HD and 11 whites on HD. I talked to a number of patients of both races, but I was not able to complete

formal interviews on everyone. Sometimes patients changed dialysis modes after they had agreed to the formal interview, or even after part of the formal interview had begun. Since patients had to be on their dialysis mode for six months or more, I had to exclude those patients who switched dialysis modes. I was unable to begin, or finish, some interviews because the patients passed away before I could get back to them. (On a happier note, one patient who had agreed to the interview was able to get a transplant before I had a chance to interview her.) I talked to patients for a long time, usually several hours, and the interviews were often not done all in one sitting.

Table 1. Sample sizes of dialysis patients, by race, sex and type of dialysis. Chi-Square analysis showed no significant differences in sample size for either sex or race on either type of dialysis.

	OVERALL (N=53)		PERITONEAL N=26		HEMODIALYSIS N=27	
	MALE	FEMALE	MALE	FEMALE	MALE	FEMALE
WHITE (n=25)	11	14	7	7	4	7
BLACK (N=28)	14	14	5	7	9	7
COLUMN TOTALS	25	28	12	14	13	14

End Stage Renal Disease (ESRD) can be caused by (among other things) hypertension, diabetes, systemic lupus erythematosus, kidney infections, strep infection, cancer, drug and/or alcohol abuse and analgesic abuse. The ESRD of

the patients in this study was caused by such factors, although the cause of their disease was not always attributed to only one thing. For example, a patient might have hypertension and diabetes, or hypertension and drug abuse. Sometimes the actual cause of ESRD was unknown. I categorized the patients according to what their medical chart listed as the primary cause of ESRD. In this sample the causes of ESRD were (number of patients in parentheses): hypertension (21); Infection--including strep infection (7); unknown (7); congenital (6); diabetes (5); lupus (3); other--including renal cancer and drug and alcohol abuse (4).

Table 2 shows the marital status of these informants. About 53% were either married or cohabited. The patients in the cohabit category all related to their "significant other" as if they were a spouse. They operated as a single household and finances and responsibilities were shared as if they were legally married. Their commitment to each other was evident. Several patients had cohabited for over 10 years. These patients called their cohabitor their wife or husband. Even the children of the cohabitors were referred to as the informants' children. Because I could not always tell if someone was legally married, I sometimes had to consult the medical records.

If they marry, the spouse would be legally responsible for the exorbitant medical bills of the patient. As single

and handicapped, the patient gets government support. It is very difficult for couples who want to be legally married but the system makes it financially impossible. There may have been others in the other marital categories who had "mates" who helped them financially, etc., but did not live all the time in the informant's household. I know that several patients who were separated, divorced, and single had "friends" of the opposite sex but I do not know the full extent of their relationship.

Table 2. Marital status of dialysis patients in this research. Percentage of column category are in parentheses.

	OVERALL	PERITONEAL	HEMODIALYSIS
MARITAL STATUS	FREQUENCY (%)	FREQUENCY (%)	FREQUENCY (%)
Married	22 (41.5%)	10 (38.5%)	12 (44.4%)
Cohabit	6 (11.3%)	4 (15.4%)	2 (7.4%)
Single	12 (22.6%)	5 (19.2%)	7 (14.8%)
Separated	7 (13.2%)	3 (11.5%)	4 (14.8%)
Divorced	4 (7.5%)	3 (11.5%)	1 (3.7%)
Widowed	2 (3.8%)	1 (3.7%)	1 (3.7%)

Table 3 shows the average age of dialysis patients in this sample was 45 years, with a range of 21-73 years. The average age at onset of ESRD was about 40 years, with a range of 16-72 years. There were no significant differences in age between those patients on PD and HD. The average

period of time someone had ESRD was about five years, with a range of 5-19 years. The patients had been on their current dialysis mode for an average of about three years with a range of 5-14 years. Again, there were no significant differences between HD and PD. Also there were no significant differences by gender for any variables in Table 3. However, there was a slight difference between races. Whites had an average of four years with a diagnosis of ESRD and blacks had five and one-half years, but this difference was only significant at the .10 level. The age at onset of ESRD was also younger for blacks than for whites (44.32 vs. 36.79) but again this was significant only at the .10 level. There were no other significant differences in race for the other variables in Table 3.

Sometimes patients had other medical problems (e.g. hypertension, diabetes) before their kidneys finally reached the 10% function level. If kidney function falls below 10%, the patient must choose a type of dialysis, transplant or death. Some of these informants had to make that decision very early in life. Mike said,

> when I was in 7th grade and playing football, I began to swell up with fluid so much that my shoes didn't fit and my skin burst in some places. I weighed over 300 pounds in the 7th grade. I came home from football practice one day and was feeling so bad my mother took me to the doctor. They diagnosed me with nephritis syndrome. I was able to take medicines and stay off dialysis until I was about 20.

Table 3. Current average age of dialysis patients in sample, including average age at onset of ESRD, average years in the ESRD program and average years on current dialysis mode. Standard deviations are in parentheses. Age at onset and years with ESRD are significant at the .10 level and only for race. No other significant differences.

VARIABLE (Range)	OVERALL MEAN (S.D.)	PD (S.D.)	HD (S.D.)	WHITE (S.D.)	BLACK (S.D.)
Current Age (21-73)	45 (13.50)	44 (11.40)	46 (15.41)	48 (13.76)	42 (12.88)
Age at Onset (16-72)	40.34 (14.98)	39.15 (13.22)	41.48 (16.66)	44.32 (15.34)	36.79 (13.97)
Years With ESRD (5-19)	4.84 (4.53)	4.96 (4.99)	4.72 (4.13)	4.02 (4.74)	5.57 (4.29)
Years on Current Dialysis Mode (5-14)	3.28 (2.95)	3.08 (3.02)	3.47 (2.92)	3.24 (3.59)	3.31 (2.29)

Jacob was diagnosed with ESRD at age 19. Perhaps because of his age, he spent a lot of time in denial of his disease.

> I escaped from the hospital three times because I didn't want dialysis. I didn't think I needed it. They hadn't had time to put any access lines in my arms, so I was getting dialysis in my femoral artery in my groin. It was very painful. I finally accepted that I needed it (dialysis) after the last escape because I collapsed in the street a few blocks away. When I woke up (in the hospital) and saw the line needles in place, it was a mind-snapping experience and I told myself I'd better get used to these needles if I wanted to live. My family were the ones who helped me accept dialysis. My mother and relatives kept telling me how my little cousins looked up to me and that if I didn't get dialysis, I wouldn't be around to help them. I'm not afraid of death for myself; I went through everything for my family and I'm sorry for what I put them through. I took my family through hell, especially my Mom. But I guess I'm here for a purpose. I guess I'm

> guarded by somebody higher up. I wrecked my car and survived it. Two weeks later my kidneys failed. I could have died at either of these times and also when I was robbed at age 13 or when I was dealing drugs. I'm not afraid of death and if it's your time to go, it's your time to go.

Even older patients may have trouble accepting that they have to have dialysis. Martin, whose ESRD was more gradual, said,

> It took me a couple of years to decide to go on dialysis. When you first find out you have ESRD you totally freak and get depressed. Normally the first thing a person wants is a transplant. I'm not interested in a transplant because of the side effects. My veins were too small so they had to put in a subclavian catheter (in the collarbone area). It is scary to watch your blood go in and out of the catheter.

Although PD patients had a higher average number of years of education than HD patients (12.62 years vs. 10.96 years), the difference was significant only at the .10 level (see Table 4). The mean and mode for education was 12 years. Some of the informants in both dialysis groups had some college education. Margaret reported virtually no education because of a physical ailment. Medical records show maybe 4th or 5th grade education but she reported none to me.

Table 4 also shows income of informants. The average income for these patients is $10,787 per year. Peritoneal dialysis patients make slightly more on average ($13,720 vs. $8,100). This difference is significant at the .10 level only. Differences in income may be attributed to the fact

that 5 of the PD patients were employed, while only 1 of the HD patients was employed at the time of the interview. Most income is disability or social security income. In sum, none of these variables in Table 4 are statistically significant (at conventional levels) between HD and PD. There were also no significant differences by race and sex for any variables in Table 4.

Table 4. Socioeconomic status of patients, including education, yearly income and employment status at time of interview. Standard deviations are in parentheses. Differences significant only at .10 levels.

	OVERALL (S.D)	PERITONEAL (S.D.)	HEMODIALYSIS (S.D.)
Education	11.77 (3.20) Range 0-18	12.62 (2.35) Range 8-18	10.96 (3.72) Range 0-18
Yearly Income	$10,787 (10391)	$13,720 (12299)	$8,100 (7357)
Employment Status	47 no job 6 employed	21 no job 5 employed	26 no job 1 employed

Many patients in this study expressed a belief that God was helping them to cope with their ESRD. Studies (Foster 1973, Carosella 1986) indicate a relationship between survival, lower levels of depression and membership in religious groups, especially Catholicism. Almost 72% (71.7%) of the patients in my study claimed to belong to a formal religious denomination. There was only one Catholic in the group; all others belonged to some form of Protestant denomination. However, only 25 patients (47.2%) said they

attend church, even on a part-time basis. The rest (52.8%) never attend church services. There were no statistically significant differences between HD and PD in church attendance. However, there were significant*** differences in racial categories and church attendance (Table 5). Out of all the blacks in my sample, 75% of them attend church, while 72% of whites do not attend. The differences between males and females was only significant at the .10 level (64% of women attend church and 60% of men).

Table 5. Frequency of church attendance by racial categories. Percentages are of the row variables. Chi-Square significant at $p < .001$ for differences in church attendance by race, but only significant at .10 for sex.

	CHURCH ATTENDANCE	
	NO Frequency (%)	YES Frequency (%)
WHITE	18 (73%)	7 (28%)
BLACK	7 (25%)	21 (75%)
MALES	15 (60%)	10 (40%)
FEMALES	10 (36%)	18 (64%)

Table 6 shows the pre-ESRD occupational status of patients in this study. Occupational levels are shown overall and by dialysis type. High status occupations were business owners and high level managers. Middle status occupations were teachers, clerical, electricians and skilled labor. Low status occupations included service workers, drivers and manual labor. Those in the "not employed" category had never worked outside the home. There

were both men and women in this category. Peritoneal patients tended to have more middle and high status occupations than did hemodialysis patients. Most (51.8%) of the HD patients had been in low status jobs before they got ESRD. There were no significant differences between HD and PD groups as to job status level; however, there were significant* differences between racial categories (Chi-Square 8.21, p-value .042). Most of the black patients (53.56%) had also been in lower status jobs before ESRD.

Table 6. Table of job status, overall and by dialysis type and by race. Percentages are of column variables.

JOB STATUS	OVERALL Freq. (%)	PD Freq. (%)	HD Freq. (%)	WHITE Freq. (%)	BLACK Freq. (%)
Never Worked	6 (11%)	2 (7.7%)	4 (14.8%)	3 (12%)	3 (10.7%)
Low Status	21 (40%)	7 (26.9%)	14 (51.9%)	6 (24%)	15 (53.6%)
Middle Status	18 (34%)	12 (46.2%)	6 (22.2%)	9 (36%)	9 (32.1%)
High Status	8 (15%)	5 (19.2%)	3 (11.1%)	7 (28%)	1 (3.6%)

The preceding has described the socioeconomic variables of the informants interviewed in this study. There were no statistically significant differences found between dialysis populations for any of these variables (at traditional levels of significance). Income and education were different between dialysis populations only at the .10 level. There were some significant differences in race and gender categories in several variables.

The Structure of the Social Networks

During interviews with these dialysis patients, I measured a great many social network structural variables, including density, multiplexity, frequency of contact, reciprocity, network composition, perceived intensity of relations, and length of time in relationship with network members. Some of these variables had further internal measurements. For example, I not only measured total density, but also density of friends, relatives, others, etc. Similarly, total network size was also measured according to counts of particular relational types. Informants have known their network members, on average, for about 20 years (Table 7), with a range of zero to 67 years. The difference between PD and HD for this variable (18.88 years vs. 21.04 years) is significant*.

The difference between PD and HD is highly significant*** for frequency of contact between informants and their network members (Table 7). Peritoneal patients had contact with their network members an average of every 102 weeks, while HD patients had contact about every 47 weeks. There is considerable variation in these data and clearly, these means are affected by the astronomical standard deviations. Still, the differences are significant. The standard deviations are due to the fact that four network generators were used to compile the network members. Thus, the total network was not restricted

to only those individuals the informants interacted with regularly. In fact, some of the informants had not seen some network members in a great many years.

Table 7. Average number of years that patients had known their network members, and frequency of contact with them. Data shown overall and by dialysis mode. Standard deviations in parentheses.

	OVERALL (S.D.)	PERITONEAL (S.D.)	HEMODIALYSIS (S.D.)
Number of Years Known Range 0-67 Years	19.86 years (292.79)	18.88 years (15.03) *	21.04 years (15.94)
Frequency of Contact Range 0-3120 Weeks	76.53 weeks (292.79)	102.01 weeks (327.77) ***	46.71 weeks (242.57)

* p=.0478
*** p=.0002

Frequency of contact is also significant* between races. However, there were no significant differences found between the sexes on frequency of contact or years known. Black patients, regardless of dialysis type, have a shorter contact interval than whites. Blacks, on average, contact their network members on average every 39.34 weeks (S.D. 76.75), while whites' contact interval is 106.59 weeks (S.D. 120.78). These results could be due to the fact that there are more blacks on HD in my data, but no significant differences in my sample size were revealed by Chi-Square analyses.

I grouped the informants' network members into categories of relatives, friends and acquaintances. For this analysis, everyone who was not classified as a friend or relative was put into the acquaintance category. As expected, Table 8 shows relatives were in contact with informants more frequently than were others. Relatives were in contact almost four times as often as friends (every 22 weeks vs. 87 weeks) and ten times as often as acquaintances (22 weeks vs. 224 weeks). Friends were in contact about two and one-half times as often as acquaintances (every 87 weeks for friends vs. every 224 weeks for acquaintances). Again, variability in these data make the standard deviations enormous. Analysis of Variance (ANOVA) for frequency of contact between relatives, friends and acquaintances showed very significant*** differences ($F=36.88$, $p=.0001$) between groups.

In a study of information flow between network members, Shelley et al. (1990) found that relatives transmitted news four times faster than friends and ten times faster than acquaintances. This rate of news transmission with a healthy informant population is exactly the same rate as dialysis patients were in contact with their relatives, friends and acquaintances. Since contact usually involves news transmission of some kind (even trivial news), there seems to be no differences between healthy and ESRD

populations regarding amount of contact with network members.

Table 8 also shows the amount of time patients had known their relatives, friends and acquaintances. Patients had known their relatives, on average, for about 26 years (26.26), and their friends for almost 14 (13.85) years. Thus, relatives had been known almost twice as long as friends. Acquaintances had been known almost 10 years. Analysis of Variances for differences in amount of time patients had known their network members was also highly significant*** (F=137.06, p=.0001).

Table 8. Frequency of contact and years that informants and network members have known each other, categorized by type of relation. ANOVA for frequency of contact: F=36.88 (p.0001); ANOVA for years known: F=137.06 (p.0001).

TYPE OF RELATION	FREQUENCY OF CONTACT (IN WEEKS) (S.D.)	YEARS KNOWN MEAN (S.D.)
RELATIVES	21.89 (129.41)	26.16 (14.92)
FRIENDS	87.33 (313.65)	13.85 (12.92)
ACQUAINTANCES	223.51 (493.22)	9.90 (11.18)

Table 9 shows the actual number of relatives, friends and acquaintances listed as social network members of the ESRD informants. Overall, these informants mentioned about eleven relatives, five friends and four acquaintances. Although there were no significant differences between groups, PD patients had more network members in each category than did HD patients, with HD patients having about one less friend and one less acquaintance than PD patients.

Table 9. Number of relatives, friends and acquaintances of informants in this study overall and by type of dialysis. There were no significant differences between PD or HD.

	OVERALL (S.D.)	PD (S.D.)	HD (S.D.)
RELATIVES	10.79 (6.84)	10.96 (7.25)	10.63 (6.55)
FRIENDS	5.21 (4.82)	5.73 (4.24)	4.70 (5.36)
ACQUAINTANCES	3.75 (4.69)	4.42 (4.54)	3.11 (4.83)

Table 10. Number of relatives, friends and acquaintances of patients grouped by race and gender of patients. There were significant** differences in acquaintances in race category only.

	WHITE (S.D.)	BLACK (S.D.)	MALE (S.D.)	FEMALE (S.D.)
RELATIVES	9.88 (7.25)	11.61 (4.66)	9.44 (6.67)	12.00 (6.87)
FRIENDS	6.00 (5.12)	4.50 (4.51)	4.61 (.92)	4.75 (5.05)
ACQUAINTANCES	5.88 ** (5.80)	1.86 (2.14)	3.44 (3.85)	4.04 (5.39)

However, when relatives, friends and acquaintance groups are separated by race and gender categories, some significant differences are observed (Table 10). Whites had significantly** more acquaintances than did blacks (5.88 vs. 1.86). White patients also cited more friends than black patients did (6.00 vs. 4.50), but this difference was not significant. Blacks cited more relatives (11.61 vs. 9.88) but again this was not significant. There were no significant differences between men and women with regard to number of relatives, friends and acquaintances; however, women cited more network members in each group.

Historically, in the social support literature women have been cited as social network members more often than have men (Bernard et al. 1990). This is also true overall in the present study. Table 11 shows that although there were no significant differences, women were cited slightly more often than men. However, this is not always true when the dialysis groups are considered. Peritoneal dialysis patients cite slightly more men in their networks than did HD patients (10.73 vs. 8.66). Peritoneal patients also cited more women (10.38 vs. 9.78). Perhaps this could be due to the fact that several PD patients in this study were currently employed and thus saw more people during the workday. Also, males have been cited more often than females when using a network generator that is occupation/location oriented (Bernard et al. 1990).

Table 11. Average numbers of male and female network members (alters) cited by ESRD patients, overall and grouped by dialysis type. There were no significant differences bewteen dialysis populations.

	OVERALL PATIENTS (S.D.)	PD PATIENTS (S.D.)	HD PATIENTS (S.D.)
MALE ALTERS	9.68 (5.65)	10.73 (6.47)	8.66 (4.63)
FEMALE ALTERS	10.08 (5.82)	10.38 (5.34)	9.78 (6.33)

Racial composition of social network members (called "alters" show no significant differences between dialysis populations (Table 12), although PD patients cite more white alters (13.42 vs. 7.69) and HD patients cite more black

alters (10.37 vs. 7.69). In general, black alters were cited less often than white alters.

Both black and white patients cited significantly*** more alters of the same race as the patients who cited them. This is to be expected since, in general, people have social network members much like themselves. Table 13 shows this tendency but also shows that female patients cited more white alters than black alters (12.04 vs. 8.75). On the other hand, males cited slightly more black alters than white alters (9.40 vs. 9.20), but these differences are not significant.

Table 12. Social network members of informants, overall and by dialysis and racial categories. No significant differences were found between dialysis categories.

	OVERALL PATIENTS (S.D.)	PD PATIENTS (S.D.)	HD PATIENTS (S.D.)
WHITE ALTERS	10.70 (6.84)	13.42 (14.86)	8.07 (10.09)
BLACK ALTERS	9.06 (9.86)	7.69 (9.02)	10.37 (10.60)

Table 13. Comparison of average number of black and white social network members of patients. No significant differences between males and females but highly significant differences between black and white patients.

	WHITE PATIENTS (S.D.)	BLACK PATIENTS (S.D.)	MALE PATIENTS (S.D.)	FEMALE PATIENTS (S.D.)
WHITE ALTERS	20.96 *** (11.87)	1.53 (2.54)	9.20 (10.73)	12.04 (14.50)
BLACK ALTERS	.80 *** (2.63)	16.43 (7.84)	9.40 (9.94)	8.75 (9.95)

A comparison of the gender of social network members cited by these patients (Table 14) shows that male and female patients do not differ significantly in citing male and female alters. However, male patients cite slightly more males (9.76 vs. 9.61) than did females and women cite more females than did males (11.18 vs. 8.84). White patients cited significantly** more males in their social networks than did blacks (11.88 males vs. 7.71 males). Blacks cited more females than males (10.25 females vs. 9.88 females) but this was not significantly different.

Table 14. Comparison of average number of male and female social network members of patients. No significant differences bewteen male and female patients; however, white patients cited significantly** more males.

	WHITE PATIENTS (S.D.)	BLACK PATIENTS (S.D.)	MALE PATIENTS (S.D.)	FEMALE PATIENTS (S.D.)
MALE ALTERS	11.88 ** (6.14)	7.71 (4.42)	9.76 (5.26)	9.61 (6.08)
FEMALE ALTERS	9.88 (6.11)	10.25 (5.66)	8.84 (4.13)	11.18 (6.89)

Intensity of relation has been theorized as an important component of the strength of social tie (Granovetter 1973, 1982; Marsden and Campbell 1984). Table 15 presents the perceived relationship intensity between informants and their network members. These data are from the entire dataset, with the results of all four network generators for all informants combined. Although there were no statistically significant differences in intensity of

relation and type of dialysis, there are some differences between those two populations.

Table 15. Frequency of informants' perceived intensity of relation with their network members, overall and by type of dialysis. Percentages are of the column variables. Frequencies are of the entire dataset of alters cited.

INTENSITY OF NETWORK RELATIONS	OVERALL Frequency (%)	PERITONEAL Frequency (%)	HEMODIALYSIS Frequency (%)
Unfriendly	12 (1.1%)	8 (1.5%)	4 (0.8%)
Neutral	158 (15.1%)	104 (18.9%)	54 (10.8%)
Not Close, but Friendly	205 (19.6%)	99 (18.0%)	106 (21.3%)
Close	303 (28.9%)	140 (25.5%)	163 (32.7%)
Very Close	369 (35.2%)	198 (36.1%)	171 (34.3%)

The counts in each cell of Table 15 are the numbers of network members who would fall into that category. In general, those network members to whom one feels "very close" can be counted on for help in any situation. Those who are "close" can be counted on similarly. If we add the two categories for each dialysis mode, the result is virtually the same (338 for PD, 334 for HD). It is interesting to note that PD patients have almost twice as many neutral network members as HD patients. On the other hand, PD patients have exactly twice as many network members whom they would classify as "unfriendly." There are even some spouses or other relatives in the "unfriendly" and "neutral" categories, for both PD and HD. Although there were no significant differences between dialysis types, the

average intensity of relation for black and white patients is significantly*** different. White dialysis patients, regardless of dialysis type, have an average relation intensity of 3.6 (S.D. .55) and black patients have an average relation intensity 4.6 (S.D. .68), significantly** higher. (Recall that closeness was measured on a scale in which 5 = very close, 4= close, etc.) There were no significant differences between males and females as to intensity of relation. I found a low, negative but highly significant correlation between intensity of relation and frequency of contact r=-.28, p=.0001). This means that the lower the time interval between contact, the closer one is to that network member. There was also a low, positive but highly significant correlation between intensity of relation and the time a network member has been known (r=.27, p=.0001) Normally, these correlations are too low to be reported but their significance points to differences of interest. These correlations just illustrate the natural tendency of people to become "closer" as they have more contact with each other.

Patients discussed intensity of relation ("closeness") to their social network members. Bill, a PD patient, said, "I am closer to people now than I have ever been." Valarie, also on PD, noticed some differences and said, "there were some changes in my social network since ESRD. Some

relatives are not as close now but some friends got closer." Misty, an HD patient, said,

> My family is a little more conscious of asking about my health. My parents call me more. My social ties are either of two extremes--closer or cut off. Some friends call. But because of my dialysis schedules I lost some friends.

Table 16 shows some other variables which describe the quality of network relations. Multiplexity is usually defined as the number of different roles that network members occupy at once. Unfortunately, the variable in this dataset is not measured that way. The Myers Resources and Social Supports Measure stipulated that the informants tell whether or not they did either one activity or more than one activity with a particular network member. This turns out to be more of a measure of frequency of contact for these data because informants perceived the question to be couched in those terms. Often, informants would say that they spent a lot of time with person X, so they chose the "more than one activity" category. After obtaining the counts for each informant, the percentage of "multiplex" relations was computed so that informants could be compared. The range for "multiplexity" was from a low of 14% to a high of 100%, with an average about 50% (58.15%).

The amount of reciprocal relations in an informant's network was also figured this way. Each network member was evaluated as to whether that person "gave an equal amount in the relationship," or whether the informant gave more, or

the network member gave more. Each informant's network was divided into the percentage of each kind of relation in the entire network. Thus, these three variables should total 100% of each informants' network. For these informants, the most common type of relation (57%) was the "equal" relation. The next highest type of relation was that in which the patient gave more (23%) and finally, 19% of the relations were categorized as the network member giving more to the patient.

The final variable in Table 16, "reciprocity score," was derived by assigning a -1 to the "they give more" responses, and a +1 to the "I give more" responses, and giving a zero to the "equal reciprocity" response. Thus an informant who felt he or she was giving more than receiving could end up with a positive score as positive as the number of network members listed. Indeed, the range for this variable is from -16 to +21.

Table 16. Reciprocity and multiplexity of overall sample. Standard deviations are in parentheses. Range for all variables (except reciprocity score) is percent of row variable.

NETWORK VARIABLES	RANGE	MEAN (S.D.)
MULTIPLEXITY	14 to 100%	58.15 (26.95)
PATIENTS GIVE MOST IN RELATIONSHIP	0 to 95%	22.72 (26.00)
ALTERS GIVE MOST IN RELATIONSHIP	0 to 100%	18.51 (23.57)
EQUAL RECIPROCITY	0 to 100%	56.51 (31.00)
RECIPROCITY SCORE	-16 to 21	1.08 (5.22)

Table 17. Comparison of multiplexity and reciprocity of hemodialysis and peritoneal dialysis. Standard deviations in parentheses. Range for all variables (except reciprocity score) is percent of row variable.

NETWORK VARIABLES	PERITONEAL (S.D.)	HEMODIALYSIS (S.D.)
MULTIPLEXITY	59.81 (27.47)	56.56 (26.86)
PATIENTS GIVE MOST IN RELATIONSHIP	17.35 (18.53)	27.89 (31.07)
ALTERS GIVE MOST IN RELATIONSHIP	14.73 (24.53)	22.15 (22.46)
EQUAL RECIPROCITY	65.38 (28.91) *	47.96 (31.03)
RECIPROCITY SCORE	.85 (3.39)	1.33 (6.58)

* p-value <.05

Table 17 shows these same variables categorized by type of dialysis. Multiplexity is a little over 55% of the relations for both PD and HD, and there is no significant difference between the two. However, there is a significant* difference between PD and HD in the "equal reciprocity" category, with PD having 65.38% reciprocal relations and HD having only 47.96%. Because this variable and the other two variables measuring who "gives more" total 100%, the result is that those two variables are lower for PD patients. Thus the HD patients "give more" to their alters (28% vs. 17% for PD patients) and more than the overall average of 23%. Some patients mentioned that they felt they were asked to do a lot by their network members, and maybe they were not really up to the task. There were

no significant differences for race or gender for any variables in Table 17.

Table 18 deals with the social support variables found in the Myers network generator. The social supports measured by this variable are advice, praise or criticism, social activity, help, and emotional support. According to directions for administering this instrument, the informant is asked to rate each network member as to the satisfaction with each type of support received. A scale from one to five is used, and zero may be used if the informant "would not ask for this type of support" from the network member. The informant is asked to say how important (on a one to five scale) each type of support is to him or her. Then the assigned score to each variable is multiplied by the total score in each support category, which is derived by adding all the network members scores in that category. The result of all this is some number either larger or smaller, depending upon the number of network members listed and the importance assigned to the support category by the informant.

This measure of social support is an excellent example of the confusion rampant in social support measurement. It is impossible to really compare informant networks because of the different numbers cited and the different weights assigned to each support category by the informant. In addition, the category, "praise or criticism" was very

confusing to most of my informants. This item asks two questions at once which might have opposite answers. One might be satisfied with the amount of criticism from a network member and wish to have more praise, or vice versa. Informants eventually ended up choosing one of either praise or criticism to evaluate. Although I think this measure of social support is practically worthless, I have included it as Table 18 to look at the differences between PD and HD. There is one difference which is slightly significant (only at the .10 level) but it is in the "criticism or praise" category, which is uninterpretable. The only thing one can say about Table 18 is that PD patients have more "social support" than HD patients, but I am not at all confident this measurement of social support is valid.

Table 18. Social support variables, weighted according to patient's evaluation of specific support received.

SOCIAL SUPPORT VARIABLES	RANGE	OVERALL AVERAGE (S.D.)	PERITONEAL (S.D.)	HEMODIALYSIS (S.D.)
ADVICE	0-545	58.15 (26.95)	126.08 (126.14)	95.37 (77.45)
CRITICISM OR PRAISE	0-476	90.79 (94.43)	112.96 (110.88)	69.44 (71.05)
SOCIAL ACTIVITY	0-460	127.83 (113.70)	149.73 (128.31)	106.74 (95.31)
HELP	0-675	181.53 (154.89)	216.23 (172.05)	148.11 (130.98)
EMOTIONAL SUPPORT	0-680	155.72 (134.24)	172.23 (161.21)	139.81 (102.55)

So far I have looked only at variables which describe the relations occurring in the network. Now I will examine the more basic structural variables.

Table 19 lists network variables which primarily measure network size and density. Size is measured in total and by size of various subgroups: relatives, friends and others. Density is measured in total and also for network subgroups. Recall that I am measuring density in the traditional manner (as the total number of network members who know each other divided by the number of possible pairs who could know each other) instead of using just the count of relations who knew each other.

As shown in Table 19 there were some categories in which there were no network members and no density. On the other hand, there were informants who had quite a number of network members and often 100% density in some subcategories. As expected, the category of "relative" had a high percentage of density, with an average density of 95.87%. The average overall network density was 87.29% which is also quite high. The density of friends was considerably lower, only 30.83%, and very small for others in the network, a mere 8.25%.

Looking at Table 19, the average network would have about 12 important people in it, 9 of whom were relatives and maybe a friend or two. There may or may not be an "other" cited. The overall network, which comes from

Table 19. Average network size, and range of social network variables involving size and density of network. Standard deviations in parentheses.

NETWORK VARIABLE	RANGE	MEAN (S.D.)
Number of People In "Important People" Network	0-31	12.26 (7.29)
Number of Relatives in "Important People" Network	0-32	9.43 (6.43)
Number of Friends in "Important People" Network	0-11	1.94 (2.89)
Number of Others in "Important People" Network	0-15	0.85 (2.80)
Total Network Members Overall	4-46	19.92 (10.22)
Total Number of Friends Overall	0-25	5.45 (5.05)
Total Number of Relatives Overall	0-32	10.92 (6.84)
Total Number of Others Cited Overall	0-21	3.77 (4.73)
Total Network Density	11-100%	86.29% (21.50)
Density of Relatives	0-100%	95.87% (15.85)
Density of Friends	0-100%	30.83% (43.04)
Density of Others	0-100%	8.25% (26.72)

combining network members gleaned from all four network generators, would have an average of about 20 people in it, with 11 relatives, 5 friends and 4 others.

According to Table 20, the average number of network members is about the same for PD and HD patients, although

Table 20. Network variables as in Table 19, for both peritoneal and hemodialysis. Standard deviations in parentheses.

NETWORK VARIABLE	PERITONEAL (S.D.)	HEMODIALYSIS (S.D.)
Number of People In "Important People" Network	12.96 (8.08)	11.59 (6.52)
Number of Relatives in "Important People" Network	9.69 (6.92)	9.19 (6.04)
Number of Friends in "Important People" Network	2.19 (2.47) *	1.70 (3.29)
Number of Others in "Important People" Network	1.08 (2.73)	0.63 (2.90)
Total Network Members Overall	21.23 (10.35)	18.67 (10.11)
Total Number of Friends Overall	6.35 (4.15) *	4.59 (5.73)
Total Number of Relatives Overall	11.15 (7.20)	10.70 (6.61)
Total Number of Others Overall	3.88 (4.22)	3.67 (5.26)
Total Network Density	84.88% (20.70)	87.63% (22.55)
Density of Relatives	94.29% (20.87)	97.41% (8.86)
Density of Friends	45.50% (45.64) *	16.70% (35.77)
Density of Others	12.08% (32.50)	4.56% (19.58)

* $p < .05$

in every subcategory PD patients have more network members than did HD patients. This difference is only significant* in the case of number of friends in the "important people" network (2.19 for PD vs. 1.70 for HD) and total number of friends cited (6.35 for PD vs. 4.59 for HD). However, having an extra network member or two may make a big difference in individual networks. Sometimes it is that network member who recognizes the need for treatment. Michele had symptoms of ESRD such as nausea, vomiting, loss of appetite, and shortness of breath. She was too sick to go to the doctor. Michele's young daughter decided that her mother was seriously ill and got her to a hospital.

Sometimes even a family member can not see what is going on, maybe because they are too close to the situation. Anna had gotten so tired because of ESRD that she had to take a nap after only as much exertion as taking a shower. A neighbor happened to come over to the house and asked Anna's husband, "isn't it about time we took her to a doctor?"

Overall density and density of relatives is a bit higher for HD patients, but not significantly so. However, the density of friends is significantly* different, with PD patients having 45.5% density and HD patients only 16.70%. Density of others in the network is four times higher for PD patients as HD patients, but this is not statistically significant.

Table 21. The same variables as Table 20, but for racial and gender categories. Standard deviations in parentheses.

	WHITE (S.D.)	BLACK (S.D.)	MALE (S.D.)	FEMALE (S.D.)
IMPORTANT PEOPLE NETWORK TOTAL	12.20 (8.80)	12.32 (5.79)	10.88 (6.06)	13.50 (8.15)
IMPORTANT PEOPLE NETWORK RELATIVES	8.56 (7.07)	10.21 (5.83)	8.04 (6.10)	10.68 (6.57)
IMPORTANT PEOPLE NETWORK FRIENDS	2.28 (2.70)	1.64 (3.08)	2.00 (3.10)	1.89 (2.77)
IMPORTANT NETWORK OTHERS	1.36 (3.75)	.39 (1.45)	.72 (1.62)	.96 (3.56)
TOTAL NETWORK MEMBERS	21.92 (11.25)	18.14 (9.03)	18.64 (8.28)	21.07 (11.71)
TOTAL # FRIENDS	6.36 (4.91)	4.64 (5.12)	5.88 (4.80)	5.07 (5.33)
TOTAL # RELATIVES	9.92 (7.20)	11.82 (6.50)	9.48 (6.72)	12.21 (6.81)
TOTAL # OTHERS	5.96 (5.77) **	1.82 (2.28)	3.64 (4.0)	3.89 (5.38)
TOTAL NETWORK DENSITY	80.52 (26.19)	91.43 (14.91)	83.24 (19.41)	89.0 (23.21)
DENSITY OF RELATIVES	94.04 (21.27)	97.50 (8.71)	93.68 (21.54)	97.82 (7.94)
DENSITY OF FRIENDS	40.0 (44.65)	22.64 (40.60)	33.48 (46.13)	28.46 (40.79)
DENSITY OF OTHERS	9.48 (27.75)	7.14 (26.23)	16.00 (37.42)	1.32 (5.0)

Table 21 shows these same variables which were in Table 20 but now grouped according to race and sex. There was one significant** difference in this table. The number of "other" network members was higher for whites than it was for blacks (5.96 vs. 1.82). White patients also had a higher density of friends than did blacks (40 vs. 22.64), but this was significant only at the .10 level. Also the number of relatives in the "important people" network was higher for women than it was for men (10.68 vs. 8.04), but significant only at the .10 level. In general, women had more overall network members, more relatives and a higher overall network density. Blacks had a higher density overall and more relatives also. Whites and males both had more friends than did blacks and females. Also, whites and males had a higher density among their friends than did blacks and females.

In the Myers instrument, the raw counts of network members who know each other are not a measure of network density and they cannot be used to compare network structural density. However, they are valuable as counts of a particular type of relation. Thus a group of people can have a particular quantity of network members who know each other. (This is called connectedness and is used in the formula to compute network density.)

Table 22 shows the counts of network members who know each other. The differences between PD and HD categories

Table 22. Average number of informant network members who knew other members of the informant's network. Standard deviations in parentheses.

Number of Informant's Network Members Who Know Each Other	OVERALL (S.D.)	PERITONEAL (S.D.)	HEMODIALYSIS (S.D.)
Total Number Range 0-37	11.37 (6.53)	11.81 (7.11) *	10.86 (5.75)
Number of Relatives Range 0-31	9.57 (6.33)	9.84 (6.72)	9.25 (5.86)
Number of Friends Range 0-11	1.50 (2.47)	1.53 (1.89)	1.47 (2.99)
Number of Others Range 0-12	0.31 (1.18)	0.39 (1.24)	0.26 (1.11)

* p =.0632

are small, and slightly significant. The difference in average total count of dense relations is only significant at the .10 level (11.81 for PD vs. 10.86 for HD). The reason the differences are so small is shown in the range of these variables. The highest number of dense relations which could occur is 37, and usually it is much less. The network generators used in this particular research do not generate large numbers of network members. There are no significant difference between the number of connected relations with regard to friends (1.53 for PD vs 1.47 for HD) and others (.39 for PD vs. .36 for HD). Remember that this does <u>not</u> say that their network densities are

different, just that they have more counts to figure into the formula.

Relatives are Relative

Cubitt (1973) calls attention to the problem of categorization of people. In her research, some people who stated that they had no "friends" were found to have more intimate relations with network members than those who considered many people as friends. Cubitt also brings up the possibility of nonreciprocal relations, such that a network member may be categorized as close or "a friend", etc., while that network member may categorize the relation differently. Fischer (1982) also found that "friend" can mean different things in different contexts and cultures.

In talking to these ESRD patients, I found some confusion in the terminology used for friends and relatives. Some good friends are considered relatives. For example, Tanya considers "godchildren" as blood relatives and told me that one in particular was her daughter/sister. They were raised sort of together as sisters even though the patient is older. The godsister's mother died and then Tanya's mother "sort of" raised her. Then when Tanya's mother died, this godsister relationship turned into a godmother relationship. Another patient, Dillan, is close to a large cohort of neighborhood kids his age whom he considers as "brothers and sisters." They all grew up together and were "in an out of each other's houses all their lives (even

now)." At first he called these people his sisters and brothers when he was telling me his relationship to them. But they are not really sisters and brothers; he just feels very close to them. Also, patients call cohabitors their spouses. Normally a spouse becomes a relative, and the spouse's relatives also become relatives (in-laws). Even with a legally married couple, some people categorize their in-laws as relatives and others categorize them as relatives of their spouse. So, I decided to have a separate category for fictive kin, cohabitors and relatives of cohabitors because the lines between who is a relative and who is not are quite fuzzy.

Table 23 shows all the relation types cited as social network members of the kidney patients in this study. Most of the member categories are quite similar on each type of dialysis. The largest category overall and for PD and HD patients is that of "relative by blood." This category contains any blood relative who is not a spouse, parent or child. Brothers and sisters, aunts and uncles, and cousins are all part of this category. For purposes of my analyses, it was necessary to categorize people by relatives, friends and acquaintances. Thus, I combined those legally married and cobabitors into the relatives category, along with other types of relatives, including relatives by marriage. However, I did not include fictive kin in the relatives category. Their relationship to an informant may be "like a

Table 23. Kinds of network members, shown overall and by dialysis mode. Percentages are for column variables.

KINDS OF NETWORK MEMBERS	OVERALL Frequency (%)	PERITONEAL Frequency (%)	HEMODIALYSIS Frequency (%)
Legally Married Spouse	22 (2.1%)	10 (1.8%)	12 (2.4%)
Child	103 (9.8%)	61 (11.1%)	42 (8.4%)
Parent	39 (3.7%)	20 (3.6%)	19 (3.8%)
Blood Relative	326 (31.1%)	140 (25.5%)	186 (37.3)
Friend	229 (21.9%)	132 (24.0%)	97 (19.5%)
Acquaintance	95 (9.1%)	60 (10.9%)	35 (7.0%)
Relative by Marriage	74 (7.1%)	49 (8.9%)	25 (5.0%)
Professional Caregiver	74 (7.1%)	33 (6.0%)	41 (8.2%)
Co-Worker	20 (1.9%)	16 (2.9%)	1 (0.2%)
Cohabitor	5 (0.5%)	8 (1.5%)	2 (0.4%)
Relative of Cohabitor	3 (0.3%)	2 (0.4%)	1 (0.2%)
Former Spouse	2 (0.2%)	1 (0.2%)	1 (0.2%)
Fictive Kin	14 (1.3%)	2 (0.4%)	12 (2.4%)
Clergy	9 (0.9%)	5 (0.9%)	1 (0.2%)
Neighbor	22 (2.1%)	8 (1.5%)	14 (2.8%)
Former Romance	4 (0.4%)	3 (0.5%)	1 (0.2%)
Present Romance	5 (0.5%)	3 (0.5%)	2 (0.4%)

sister" but there are some important differences. One difference is that blood kin or kin by marriage have more of a tie of obligation than someone who is a very good friend. It may be argued that cohabitors would fall into the same category of fictive kin, but I believe they are definitely in the role of a spouse. These couples have the same financial and emotional characteristics as a legally married couple.

Almost every physician I talked to predicted that, since the fellow patients and caregivers are with the ESRD patients so much, those alters would surely be a large portion of the network of ESRD patients. However, no ESRD patient listed a single fellow patient. Perhaps other patients would have been listed if different network generators had been used. After all, the network you get depends on the question you ask. The percentage of professional caregivers (physicians, nurses, technicians, etc.) is (7.1%), lower (6.0%) for PD patients and higher (8.2%) for HD patients. If a patient listed caregivers in the network at all, usually there were quite a number of them, almost as if they were a single entity. However, most patients did not cite any professional caregivers in their networks.

Relatives form a large part of the ESRD patient's social network. There is usually much more family contact if the patient is at home and not employed anymore. Having

ESRD can improve family relations. Margaret said "my friends and family are more attentive now that I am on dialysis. They call me every day and they didn't before." Many patients said that their families were closer than ever before. Matt, a PD patient, said:

> My family is just like a watchdog. If I'm late they worry if I don't call in. When I first got ESRD, my family would nag me about my medication, which I didn't like to take. My mother is still protective and doesn't want me to lift anything. I tell her I can do things. I tell her I'm just the same only I can't make water.

Some patients do not want the attention of being different. They just want to be normal. Bill told me,

> I don't want to be treated any different. I'm determined not to be different. But my family says 'don't overdo yourself.' When I first got ESRD my relatives were attentive. Now they forget I'm on dialysis. I don't dwell on my sickness and I want people to think I'm feeling well even if I'm sick.

Jenny's mother tries to take care of her even though Jenny would rather do it herself.

> My mother lives in the same apartment complex. She comes over every day and tries to do the cooking and cleaning and laundry. I tell her, 'don't treat me like a baby.' My Mom has sugar (diabetes) and takes care of me instead of watching out for herself.

Relatives are important in helping the patients adjust to their lives as ESRD patients. Brandon said,

> my family stayed by me while I was abusing drugs and they are the reason why I feel ok about dialysis now and am doing so well. My mother sat down with the dietician and learned my diet.

Several family members said their lives revolved around the ESRD patient in their family. Cala's mother said, "she has a very supportive family and everything revolves around her. That is why Cala is doing so well." Leonard's wife said,

> I used to be active in clubs in our city. But I have curtailed everything and I have my nose to the grindstone now and my life revolves around Leonard. We used to be very active and traveled a lot. We had shared home responsibilities before his illness. Now I stay home mostly and keep house doing what he used to do. I have been on a diet but now I'm off it because we are on opposite diets. He can eat what I can't and vice versa. Right now he drives himself to dialysis and I'm scared that he won't come home. Every time he leaves for dialysis I think I might not ever seem him alive again.

Relatives worry about their family members who have ESRD. Cala's mother said, "it is like living with a time bomb, because she may die at any time. I went into nursing so I could understand more, and be ready for anything." Lucy was worried about Sara, her mother, because she was having a very bad time of it. Lucy said,

> I told my mother, 'don't give up, the Lord will help you.' But sometimes I ask myself, 'why did this have to happen to my momma?' But then I think, 'the Lord has a reason for things.' My mother can't do a lot of things. I don't think even now that she accepts it. I encourage her to walk but she doesn't want to. If I'm not there, she doesn't exercise. I constantly worry about her dying, especially when she is this sick. She doesn't follow a diet. She has no appetite and doesn't want to eat. When she's with me she feels so much better. She gets three meals a day and sits in the sun.

Jason said,

> kidney disease affects the whole family. There is more stress on the family. If you have a disease, you might as well both (patient and spouse) have it. Sometimes it's like all of us are on dialysis. CAPD brings more family involvement. With hemo, you go away and do it somewhere else. You can hide dialysis on hemo. If a person sees it, they are a part of it. I never let people see me do CAPD. If they see me doing that, it becomes more real to them. They should have emotional stress clinics for kidney patients. I know CAPD patients are stressed. I imagine that hemo patients are stressed too.

Relations with Spouses

Having ESRD can cause a lot of problems in personal relationships, especially relations with spouses. Marital disruptions are common. Rick said,

> when I got a kidney biopsy my wife acted like it was the end of my life. I got a PD catheter and before I got home from the hospital my wife left me and took our newborn son with her. She hadn't even lived with it. I'm a lot different now than I was before I got on CAPD. I used to be so tired I could hardly do anything. Now I have energy again.

Most patients in this study reported good relations with their spouses. Lane said his wife was very understanding about PD. "What I feel comfortable with, she feels comfortable with. She was with me in the training classes."

Julie talked about her relationship with her spouse:

> My husband is very important to me and he is my dearest friend. But he has a child/wife problem. Sometimes I am like a child to him, requiring care and feeding, etc. Other times I can be fully like a wife, grocery shopping for us, having a full sex life, and going on with ordinary living. We love each other. He stayed with me during all my transplants and when I was near death. He lost 11 pounds when I lost so much weight. I always go with my husband's advice. He was my home hemo partner and is now my partner for CAPD, although it needs no partner. I consult with him about my

dialysis. I can do it for myself but I would rather depend on him.

Several men said that they could not have made it without their wives. Paul said,

> I don't know if I can make you understand about how my wife is. I wouldn't be here if it weren't for her. My wife was in school and we had to move close to a kidney facility so she lost credits when we moved, which extended the time it will take her to get her Bachelor's degree. My wife and I don't talk about my disease much. She doesn't know what medications I take. She ignores my disease. That's her way of coping. We are both under high stress and sometimes fight. But our relationship is better now. I think we have gotten closer after my kidney disease. I do CAPD and CCPD according to the occasion. I think my wife might prefer CCPD because it frees me from dialysis during the day. (This would make it easier for her to ignore his disease if she does not see him do PD exchanges during the day.) In general, my wife supports me on whatever decision I make about my treatment. My wife doesn't know exactly what I should eat. I started on a heart diet and then went to an ESRD diet. It's all confusing.

Bill has been sick since he was 18.

> I owe a lot to my fiance (cohabitor) for sticking by me during my illness. She is the reason I'm not dead. If it wasn't for her, I'd be a lot worse. I gave up my former drinking buddies to devote my life to her and spend time with her. I tried to break up with her when I first got sick. I was tired of trying to work on the relationship and did not see any reason for existence. But she wouldn't let us break up and didn't stop trying. My fiancee is scared about a transplant but wants me to feel better. She mostly cooks and shops. But sometimes I cook and shop too if I feel I have enough energy. We avoid Italian foods like pizza. She diets anyway and so watches what she eats too. Sometimes we splurge and add a little salt to our food. I feel a little dependent on her. She helps me with dialysis, like microwaving my bags and she cooks for me.

Older patients often depend on their spouses for help, emotionally and physically, when they get ESRD. Cindy said her husband is instrumental in seeing that she gets to dialysis. Cindy told me,

> He takes care of me. I'm not able to do housework anymore, so he does it all, even though he is in his 70s. Without my husband, I might not come to dialysis and just give up. Sometimes I don't want to go on the machine, but I've never missed a day. I might not want to go on the machine without my husband. I have terrible itching especially on my back which keeps me from sleeping. My husband scratches my back. I don't know what I'd do without my husband. I get bad leg cramps while I'm on dialysis and my husband rubs my legs while I am on dialysis. He comes with me every day. We have been married for 47 years. Another girl here, when she got sick her husband left her, with a son age 11. I don't have a lot of energy, well actually no energy. My husband does the housework, mops and waxes, cooks and shops. We eat out quite a bit. The doctors and nurses want you to eat rice and noodles.

Often older couples are like a team, almost like one person. April and her husband have been married for over 40 years. April said,

> When I went to the hospital with symptoms of kidney disease I said to my husband, 'Daddy, I'm dying.' It was 2:00 a.m. and I was wet with sweat. I called my daughter to take me since my husband can't drive. My blood sugar had dropped. My husband said to me 'we have always done things together all of our lives and we will work this kidney problem out together. When I was on hemo, we both stuck strictly to that diet.

April's husband told me, "I don't eat stuff she can't have. I told April when I found out she had kidney disease, 'we'll be in it together.'"

The Role of Professional Caregivers

A professional caregiver is someone who cares for the patient in an official capacity, i.e. a nurse, doctor, technician, etc. Dr. Edwards expressed the opinion that "patients are with a dialysis nurse a minimum of two and one-half, three times a week. She has a big influence on patients." This feeling was echoed by Wilma, an HD patient, who said, "nurses and patients have a close relationship. They go through a lot with them." Wilma did list several caregivers on her list of important people. Jason, a PD patient who also listed caregivers as people important to him, said,

> my doctor was almost like a family member, because I put so much confidence in him. He is very honest. It's like you have two families. You want the approval of both of them. You want them {the doctors and nurses} to say that you are doing things right.

Some caregivers spend a lot of time with the patients and their families. April said, "my doctor spent 2 or 3 hours with me and my husband, explaining things to us." Unless unforeseen circumstances arise, most patients would not think of switching dialysis centers. Casey, an HD patient who expressed this opinion said,

> I don't trust other people for dialysis. I'm used to and trust the doctors and nurses here. I knew of a man who got his graft messed up somewhere else. So I don't even think about that.

Caregivers literally have the lives of HD patients in their hands. Because of this, Misty took extra care to keep a "professional relationship" between her and the nurses.

> I don't want to get close to any nurses or technicians because I worry that if I am friends with one, and not another, my care might suffer.

Since all the nurses eventually took care of all patients, she did not want to cause any personality problems among the staff which would have repercussions on her.

Caregivers have often been instrumental in saving the lives of their patients. Kevin said, "the nurses have "saved my life (while on the HD machine) so many times I just doesn't know how many." One day Kevin came to the center with low blood pressure at the beginning of dialysis. While I was talking to him he began to feel bad and called a nurse over to us. She quickly took his blood pressure and it was very low. She gave him a shot of saline which took his pressure up a little and was very attentive and did not leave his side until he was stabilized. Patients can "bottom out" on the machine and if their pressure gets too low, they can die. Kevin said, "I actually had a stroke once while on the hemo machine and the nurses were able to keep me from dying."

Cindy often has trouble with her blood pressure. "Whenever I sit up, my blood pressure goes down." When that happens she can pass out and is in danger of dying. She told of a close call she had.

> I once passed out on the machine and didn't even know I was going out. Vincent noticed and others came running. They gave me smelling salts, juice and took me off the machine. My doctor asked, 'how long has she been out?' They were trying to find out if I had brain damage. If Vincent hadn't noticed me, I would have died. I feel very indebted to him.

One day while I was in a dialysis center I saw something that touched me deeply. I saw a dirty, unkempt patient on HD who seemed very depressed. After a while, Elton, a caregiver, came over and began trying to cheer him up while shining that patient's shoes. Elton seemed to be trying to give the patient some dignity. That ESRD patient, I learned later that day, had been found in a nearby trash dumpster and was discovered to be an ESRD patient and subsequently placed on dialysis.

Most of the time the relationship between patients and caregivers is nurturing and supportive for the patient. However, it is not always that way.

I was listening to a group of patients who were sitting in a waiting room waiting for their turn at HD. They were discussing how sometimes the staff is rough with them when putting the needles in to get the vein access. One man said, "the needle went once right into my bone. She seemed like she was twisting the needle." Another man said,

> that nurse had to try 7 times to get my blood and I was about to hit her. She told me, 'I know this hurts' but that didn't help things. It still hurt real bad."

Another woman also threatened physical harm to technicians who "stick" them roughly. One patient mentioned that sometimes they have to get different vein access sites (i.e. the groin or the top of the foot). They were all talking, not specifically to anyone in particular (but sometimes they were). They were talking in a way so that everyone in the room could be in the conversation if they wanted to.

They began discussing how staff members kept "goodies" such as donuts, candy, and cookies from the patients. One man said, "they have donuts back there. But they won't give 'em to us." Another patient said, "they used to give us hard candy, but no more." The significance of this is that patients are here for hours, through mealtimes (breakfast or lunch). They get very hungry and if they want to eat anything they must bring their own food. Some people bring food and others don't. They forget, or don't have the money. In fact, during this conversation, a lady was eating breakfast in the waiting room while everyone was talking to each other. People commented on how each other looked that day, or what they were wearing, etc. But all the patients who spoke in the waiting room that day seemed to convey the sense that although they were there for a service and seemed friendly to the staff, that the staff was in some way against them (or at least not completely sympathetic) and trying to keep things from the patients.

Due to the setup of a dialysis center and everyone being together in one room, it is impossible to give something to one patient and not another. Dr. Johnson said, "if I noticed that a patient had a cold, I could not dispense a sample of Robitussin to that patient unless I had samples to give to everyone." So a caregiver could only give things to patients which they could give to everyone. Some patients are diabetic and can not have certain things. Even if they could have them, there probably would not be enough to go around to everyone, which could cause hard feelings.

Janene, who is a caregiver, said that, "it is easier for nurses to work with the PD patients than HD patients because there is less frustration among the staff with PD patients." Several caregivers said, "patients are dependent on the staff to do things for them and they don't want to help with their treatment." This frustration can sometimes come out at the patients. Kelly reported hearing some nurses say, "I can drink all I want when I go home." Kelly said, "the patients don't forget that kind of a comment." Since HD patients have strict fluid limitations, this would be a particularly distressing comment.

At times the relationship between caregivers and patients is almost like a parent/child situation wherein the patients are "bad children." However, if patients are treated like bad children they are going to sometimes act

the part and not pay any attention to the one who is condescending to them. An example of this situation is that while I was interviewing an HD patient, a nurse, Fern, walked by and noticed that Jacob's ankles were crossed. Fern picked up one of Jacob's feet and put it down so his feet were side by side. Then she said, "you're not supposed to have your feet crossed." After she left, Jacob crossed his ankles again. Fern might have been successful if her attitude had been different. But she treated Jacob as subservient to her and he was not about to listen to her or do what she wanted.

Sometimes patients will do what is bad for them in order to exercise some control of the situation. The last half hour of HD can be very uncomfortable. Patients get restless, have itching, nausea, and weakness. Patients who take themselves off the machine early or do not even show up for dialysis may get no sympathy and are labeled as "self-destructive." Physicians (who feel they are trying their best to treat these patients) get frustrated and threaten the patients with discontinuance of service. Since these patients hate HD and do not want to be there, threats of discontinuance of HD do not do any good because <u>not</u> being on HD is exactly what they want. If someone prevents them from getting dialysis, then it is not their fault if they can not dialyze. Patients who try to make decisions for themselves and question the decisions that are made about their care

are labeled as "difficult patients" and are sometimes dismissed as neurotic. It is similar to the situation of a child questioning the authority of a parent who "knows what's best." The parent/child similarity was quite evident in one particular incident. Some of the patients retain some minimal kidney function even though they are on dialysis. So, for various medical tests it is necessary to find out if a patient is still able to urinate. One day I heard an adult caregiver ask an adult dialysis patient if he "could still make tee tee."

The Role of Fellow Patients

The social network generators I used did not capture fellow patients. However, they are an interesting part of the social networks of ESRD patients. Patients on HD do not always sit in the same seat and sometimes have different seatmates. Patients on PD only see other PD patients when they come in for periodic clinic visits and they may not see the same fellow clinic patients that day. Also, sometimes it seems that people as individuals do not fill a role for the patients, but the "group" provides important social support and interaction.

Patients in the nearby vicinity watch out over each other during hemodialysis. Several times while I was talking to patients, they stopped paying attention to what I was saying and got the attention of a nurse so that she

could tend to the problem of a fellow seatmate. It is important that the patients watch over each other while they are on dialysis. Nurses have to care for many patients at once and are very busy. It is a life-threatening situation if a seatmate does not help get the attention of a nurse when a fellow seatmate is in trouble.

Sometimes patients keep to themselves, because they have known fellow patients who have died. Misty said,

> There was one older man I called 'my buddy.' I used to talk to him a lot but I see he's getting worse and I worry he may die soon. So I talk to him less, maybe I just wave hi or something. I don'twant to be hurt when he dies.

Another patient said about fellow ESRD patients, "you almost want to stay away from each other. It reminds you of your own problems and is also a death reminder."

Julie said:

> Sometimes I don't like to talk to people because they will die. In 1972, when I started dialysis, all others who started with me (in her cohort) are dead. I don't want to meet new people. I don't want to talk to them about personal stuff because I will get attached to them and they will die or suffer horribly with another disease like diabetes.

The Role of Friends

Chyatte (1979) noted that the diagnosis of ESRD brings about a loss of social network members. Friends fade away because they do not want to be reminded of death or they can not stand to see a loved one go through a bad situation.

Sabrina said that before ESRD her social life was more active.

> I did everything before. Then my friends backed off like I had some contagious disease. But my family, my Mom and Dad, were there. My friends backed off and had nothing to do with me. It hurt a lot.

Brandon observed that his friends acted somewhat differently than when he first went on dialysis. "To people who don't understand dialysis, it's a nasty, scary word."

The difficulty of keeping friendships while on dialysis seems to be hard for both the patients and their friends. Jason said,

> Some friends don't want to be around sick people. They think if they hang around you, the same thing is going to happen to them. The amount of friends you have declines fast. They are afraid you are going to be talking about depressing things, like your illness. The amount of time with friends and family declines. This is not always by choice. You also shy away from your friends more because you might have to talk about it (your illness.) So they think you don't want to see them, and vice versa. It is fuzzy about whose choice it is to keep friendships alive. I get a sinking feeling sometimes that people will take things wrong.

Old friends may be doing things that landed the patient on ESRD in the first place. These friends are sometimes still participating in drinking and/or drug abuse and do not have much in common with the patient anymore. Frank said,

> I used to drink with my friends and now I can't. They ain't got time for me. They drink their beer and stuff. I used to be a hard drinker, but not now.

Tim, a patient who had been abusing drugs, said "you ain't got no friends when you are on drugs, just if you got money or drugs." Brandon said likewise, "when I was using, you have no friends or social life, only using buddies."

Sometimes patients do not have the energy to go see their friends. Leonard mentioned that he could not go see friends because they have stairs, which he can not climb anymore. Many patients call their friends often by phone.

Health Outcomes and Social Networks

Health outcomes are measured in several ways. Physical health indicators are measured by weight gain, blood chemistry values and the 95-item questionnaire on informants' physical symptoms, ailments and mental status.

Diet and Health

One of the problems of having ESRD is that it is very hard to stay on the required diet. Because the kidneys no longer filter out excess solutes, many foods must be strictly limited. Sodium, phosphorous and potassium are in nearly everything. Fruits, vegetables, dairy products, dried beans, and "greens" (collard, mustard, turnip, spinach, etc.) all contain these things. Some people are used to eating high-phosphorus or potassium-rich foods all the time.

Julie's family did not understand the delicate potassium balance involved in a renal disease diet and it caused disruptions in her family life. If potassium is low, potassium-rich foods (baked potatoes, candy, butter, etc.) are allowed, but if it is too high, they are forbidden. This makes meal planning very difficult for the cook because the diet can change from week to week, or even from day to day. Network members who deal with this have to learn about the diet fluctuations.

Many ESRD patients have stories to tell of surviving a bad reaction to a particular forbidden food. Michele said, "I fell out once when I ate bananas and so now I don't mess with them." Other people said they had breathing problems or terrible itching after eating bananas or watermelon or oranges, etc. Now they avoid those foods.

It is particularly difficult to change diet, if one's family does not change also. Cala told me that a member of her family is constantly fixing foods which she is not supposed to eat. Patients try to be particularly strict with their diet and be very good right before a blood test so that the test results will not show high levels of phosphorus or potassium. The night before a blood test, Cala's relative fixed her a tomato sandwich for supper. Tomatoes are high in potassium and are to be avoided by ESRD patients. Czaczkes and Kaplan De Nour (1978) talk about family members who overtly support the patient but covertly

communicate death wishes by "forgetting" and adding forbidden foods to the patient's diet.

A lot of family life is organized around food and celebrations involving food. Many black patients referred to any family gathering as an "eatin." Casey said,

> I can't go to the eatin' on the 4th of July. I always used to go but they have all that food and I can't eat it. So it's a torture. I do eat differently from my family. I can eat green beans but I'm not supposed to have field peas or lima beans. But sometimes I do eat them because they smell so good cooking, I can't resist. (I asked him about red beans, pinto and navy beans.) Black people don't eat those. I am supposed to be on a salt free diet because of my blood pressure but I use salt anyway, and not a substitute, because it tastes bad. I remember when I was a boy, I used to go to the smokehouse, cut off a piece of smoked ham and eat it right there.

Kidney patients are not supposed to have dried beans and greens which are a traditional part of most black families' diets. One caregiver, Russ, observed that,

> Most of these patients are black and kidney disease disrupts black family life. The focus of this disruption is diet. As the patient eats a different diet from the family, he moves away from the family circle. The result often is that the patient doesn't follow the diet.

Misty was a vegetarian before she got ESRD.

> I didn't like protein and it made me sick. Now I have to eat meat. My husband does the cooking because I am just too tired to do it. It's so awful because I can't do anything for myself. He tries to eat the same things I do. Maybe we have a pizza once in a while. I used to eat a lot of vegetables and fruit, all stuff I can't have now. I have been eating cheese and drinking milk all my life so it's hard to just cut it out. As a result I have a lot of trouble with itching, especially on the palms of my hands. I can't sleep at night.

Some families are very supportive and do not tempt the patients into eating what they should not. They modify their diets so they do not eat "bad" things in front of the patient. Tim said, "my family doesn't bring what I can't eat into the house. I tell them to but they won't. My family eats like I do."

Frank was trying to keep his wife from knowing what was on his diet because he knew she would try to keep him on that diet and make him eat what he was supposed to eat. He wanted none of that. He said, "I eat what I want. I eat lima beans, bacon and drink whiskey." I heard a fellow patient try to tell Frank one day to eat what <u>they</u> want him to eat instead. Frank bragged,

> I missed dialysis for a whole month but I finally came in because I couldn't breathe. My wife would help me eat right if she knew. My wife works and so I start cooking dinner. We go grocery shopping together. My wife is a good cook. If she cooks it, I eat it. But I can't eat a lot because I am hungry and then I lose my appetite. But I don't throw no food away. I drink soda water and V-8 juice (a no-no). I eat macaroni and cheese and watermelon. Sweets make me drink water. And with cake I want milk. I eat bananas, 2 or 3 at a time. My wife tells me, 'you ain't supposed to have so and so'.

Patients can have unusual ways of controlling their health with diet. Christina says that in general, "I don't bother with things I can't have. If I do eat something bad, I take a good laxative and work it out." Shannon said,

> I eat Argo starch and drink soda water. I used to eat one box every 2 days. My mother ate it and I tried it and liked it. They had to wash it off my babies' heads when they were born. I eat string beans and beets to

> help keep my blood built up so I don't have to have transfusions. I don't want no kidney transplant. If I'm going to die, let me die with what God gave me. I can't walk anymore like I used to and I get tired when I drink too much fluid. My great-grandchildren live with me. We take care of each other. Their momma gave them to me.

Sometimes social network members can hinder the ESRD patient from keeping to a diet. These patients are not supposed to have chocolate but Cindy says,

> I don't eat chocolate anymore. My brother-in-law brings a big sack of Reeses peanut butter cups when he comes here. He still brings them now even though I'm not supposed to have them anymore. I give them to my grandson and my husband eats some of them too.

She is not supposed to eat grilled cheese, peanut butter and all dairy products, but she does. Cindy said, "my husband gave me grapefruit juice. He thought it was good for me, but it wasn't."

Dr. Johnson reported an incident where a young woman died because her mother gave her orange juice.

> For some reason the mother thought that was all her daughter could tolerate. The daughter had no appetite and only had a taste for orange juice, so that is what her family gave her. All parties involved knew the girl was not supposed to have orange juice, even the girl.

Patients with ESRD are also supposed to avoid bananas. Leonard said, "I love bananas. My wife buys them and it's hard because I don't eat them."

One patient said it is all just too much to bear sometimes and that sometimes "to keep her sanity," she does not follow diet or take medicines as she should. This seems

to be a way to take control of part of her life. She decides that for 24 hours she is not going to take any medicine, or is not going to follow a diet.

Casey said,

> sometimes, usually about once a month, you just gotta have stuff. My wife is very strict with me about my diet. We were shopping one day and bought bologna at the grocery store and she said 'put it in the refrigerator, you ain't gonna have any.' When she left the room I got in the refrigerator and snuck a piece.

Jacob's philosophy is

> I don't want to die miserable. I want to enjoy life because you're going to die someday. Nobody knows your body better than you. If I feel bad, I would do what it takes to feel better. I eat whatever I want. Life is to be enjoyed since it is a short life. Just don't overdo.

Jesssica, an HD patient, said, "I don't care about anything until I can't have it. Then I think about it constantly." Anybody who has ever tried to diet knows exactly what she is talking about.

In Florida, watermelons are on sale at almost every corner around July 4th. This must be very hard for kidney patients. (I was influenced by all those watermelon stands to buy one myself--and I am not fond of watermelon.)

Weight Gain

Too much weight gain between dialysis treatments for HD patients or too much weight gain between clinic visits for PD patients is a sign of fluid overload. HD patients can

only have about 32 ounces of fluid a day, which is found in anything that melts at room temperature, including ice, Jello, ice cream, etc.

Kelly said,

> No one knows what it's like to have to limit fluids unless they have to do it also. It's like AA (Alcoholics Anonymous). You don't think much about water until you can't have it and then that's all you can think about. Nurses and doctors who remind patients not to consume too much fluid put that in the front of the patient's minds and make them want it more. Patients who miss medications or take too much water don't get sick, so they continue to do it. Even though they feel the weight of excess fluid, it's ok as long as you can breathe.

Russ, a caregiver, confirmed this and observed that,

> hemo patients have a lot of fluid and weight gain which is not a problem in CAPD. I think this is due to the fact that the nurses want them (HD patients) to refrain from fluid and weight gain and they tell the patients so. However, in CAPD, this is not stressed. I think the kidney patients are a touch suicidal. They don't do something, consciously or unconsciously, and then they blame their condition on the fact that something else was the cause.

Patients on PD do not have any fluid restrictions, although fluid overload for them can be caused by inadequate dialysis (either not dialyzing enough or using the wrong percentage of glucose dialysate solution). For PD patients, fluid overload is often a sign that they are not doing their dialysis enough. One patient confessed that she drank too much fluid and gained 14 pounds in two days during a holiday period. Michael Anne said,

> I'm not supposed to have collard greens, mustard greens, peanut butter or chocolate at all. (At first when I asked her if she ate them she said no, not at

all. Then as we talked about things, she gradually admitted that she has them sometimes in moderation.) I eat peanut butter about once a week, and a little bowl of greens whenever my mother fixes them. It's so difficult to completely give up something you have grown up with and the rest of your family still enjoys in front of you. Someone brought me a chocolate cake during the holidays and I ate almost the entire cake myself over the course of two or three days. My labs (laboratory scores) were very bad and my doctor threatened to give me an extra half hour in the (dialysis) chair if my labs didn't improve. I was very good after that because I couldn't take more time in the chair.

Unfortunately, a lot of patients depend on "time in the chair" to resolve their dietary indiscretions. This makes their dialysis experience more uncomfortable. The more weight the machine is expected to remove, the harder it is on a person's body. Casey said that he would not want PD because he depended on "the machine" to take weight off him.

I asked physicians, nurses, technicians and other caregivers to categorize their patients according to whether their weight gain was low, average or high for their particular dialysis mode. If there were discrepancies for each patient, I averaged all responses for that patient. The results are shown in Table 24. Most of the patients were categorized as having average weight gain. Although not statistically significant, note the differences between the PD and HD populations, especially in the area of low weight. Only one HD patient was judged low. Perhaps that is because fluid overload and weight gain is a significant problem for HD patients. Table 24 also shows that there

are practically no differences between sex and race regarding weight gain. However, there is a slightly significant (only at the .10 level) difference between men and women on weight gain. Females were judged to have average weight more often and men were often judged to have high weight gain.

Table 24. Frequency and percentages of weight gain by dialysis mode, race and sex. Differences between PD and HD patients and between males and females are significant at only the p <.10 level (p=.074). There were no significant differences between racial categories.

	OVERALL	PERITONEAL	HEMODIALYSIS
WEIGHT GAIN	FREQUENCY (%)	FREQUENCY (%)	FREQUENCY (%)
Low	7 (13.2)	6 (23.1)	1 (3.7)
Average	31 (58.5)	12 (46.2)	19 (70.4)
High	15 (28.3)	8 (30.8)	7 (25.9)

	MALES	FEMALES	WHITE	BLACK
WEIGHT GAIN	FREQUENCY (%)	FREQUENCY (%)	FREQUENCY (%)	FREQUENCY (%)
Low	3 (12.0)	4 (14.29)	2 (8.0)	5 (17.9)
Average	11 (44.0)	20 (71.43)	15 (60.0)	16 (57.1)
High	11 (44.0)	4 (14.29)	8 (32.0)	7 (25.0)

Blood Chemistries

Another measure of noncompliance is the monthly blood chemistry values. For example, Dr. Edwards said, "if a patient's phosphorous and potassium are both up then the

patient is eating something bad, too many potatoes, red meat, or dairy products."

Table 25. Average blood chemistry values for entire sample and by type of dialysis. Standard deviations in parentheses.

	OVERALL	PERITONEAL	HEMODIALYSIS
	MEAN (S.D.)	MEAN (S.D)	MEAN (S.D.)
SODIUM (mEq/L)	137.91 (4.70)	137.11 (5.44)	138.73 (3.72)
POTASSIUM (mEq/L)	4.61 (0.58)	4.36 (0.52)	*** 4.87 (0.53)
CHLORIDE (mEq/L)	97.55 (4.83)	95.48 (4.76)	*** 99.69 (3.95)
BICARBONATE (mEq/L)	22.70 (4.34)	25.43 (3.81)	*** 19.87 (2.78)
BUN (g/dL)	65.88 (15.92)	65.00 (17.39)	66.80 (14.52)
CREATININE (mg/dL)	13.63 (3.45)	13.95 (3.47)	13.30 (3.46)
CALCIUM (mg/dL)	9.45 (1.20)	9.51 (1.34)	9.39 (1.04)
PHOSPHORUS (mg/dL)	5.82 (1.51)	5.89 (1.64)	5.76 (1.38)
PROTEIN (g/dL)	6.59 (0.66)	6.27 (0.60)	*** 6.92 (0.56)
ALBUMIN (g/dL)	3.34 (0.70)	3.03 (0.79)	*** 3.65 (0.40)
HEMATOCRIT (%)	27.47 (4.79)	27.11 (4.99)	27.83 (4.64)
GLUCOSE (mg/dL)	112.65 (52.51)	121.65 (59.13)	103.31 (43.83)

Table 25 shows the averaged monthly blood chemistries for all patients in this study, overall and by dialysis mode. There are some very significant*** differences between some of the values in this table. The absolute differences

appear to be small; however, in some cases (like potassium, protein and albumin) the possible values are small in the first place and apparently minor variations are significant. These blood chemistry values are inter-related and the physician uses the entire chemical profile of a patient to determine adequacy of dialysis and compliance with medical regimen.

Protein and albumin. It is not surprising that protein and albumin are higher for HD patients than for PD patients. (protein 6.27 for PD and 6.92 for HD; albumin 3.03 for PD and 3.65 for HD). Low albumin is a sign of malnutrition and muscle wasting. It is related to low levels of protein showing up in the blood chemistries. Peritoneal dialysis causes proteins to leach out of the body along with the dialysis fluid. CAPD patients can lose 3-20 grams of protein in a 24 hour period (Foulks 1988). It is important for PD patients to eat good quality protein. Patients who are protein deficient are encouraged to eat more high-quality protein, which contains essential amino acids. At least 1.5 grams per kilogram of body weight of protein is the recommended protein intake for CAPD patients. This is about twice the normal requirement of protein for a healthy adult (Moncrief 1989). Patients are also advised to drink protein supplements. Some patients can tolerate the taste of these and some cannot. Elizabeth, a PD patient, said,

> food tastes too sweet and I'm forcing food down half the time. My main complaint about CAPD is that I have

> no taste for meat, even lunchmeat. After I started CAPD it took me 6 months before I could eat any meat. Maybe it's the medication. I have to take a liquid protein supplement. I don't follow any diet and I buy and eat whatever I feel I can eat and afford. I got burned out on fish because for a while that's all I could eat. My children shop and put food in my freezer for me, like pot pies and frozen lasagna.

Sodium, potassium, chloride and bicarbonate. Table 25 shows that there were highly significant*** differences on some of these variables for different types of dialysis. All these substances have related effects on a patient. Too much sodium can cause volume overload and edema (too much cellular fluid). But plasma sodium concentration is not an indicator of how much sodium is in the blood, because the actual amount is masked by fluid volume. Normally, high sodium blood serum values indicate water overload and low sodium values mean water deficit. Hemodialysis patients have a lot of trouble with regulation of fluid intake and staying away from dietary potassium. This substance is present in protein-containing foods, especially meat. The kidney handles sodium, hydrogen and potassium similarly, with the regulation of sodium being the primary priority (Smith 1991). When chloride concentration rises, the bicarbonate concentration falls. Too much potassium produces weakness and "twitchy" muscles and cardiac arrhythmias (potassium affects muscles, so it affects the heart). Excess potassium (hyperkalemia) can cause heartbeat abnormalities and can cause the heart to stop (American

Kidney Fund 1988a 1988b). Potassium is in foods people eat almost daily: potatoes, milk, chocolate, bananas, oranges, beans, nuts.

People eat forbidden foods even if it causes them to be hospitalized. Sabrina said, "I've been four times to the hospital as a result of eating mashed potatoes. One time I can get away with it, and another time I can't." This is because sometimes one can have forbidden foods if the amount of phosphorous or potassium in the body is not too high. Matt, on PD now, told about a time when he was on HD that he got a craving for french fries.

> I hadn't had any french fries in three or four years. So I got a big bag of ORE-IDA frozen french fries and cooked them and ate every last one and woke up in the hospital with elevated potassium. Some things don't taste good to me anymore. To me, meat is tasteless (a common complaint of CAPD patients.) I don't eat enough of it so I have to take a protein supplement. On CAPD I can pretty much eat what I want. I eat a banana every now and then and even dried beans and peas, just not to excess.

Blood urea nitrogen (BUN) and creatinine. Creatinine shows amount of skeletal muscle. It also marks the state of nutrition and tells if dialysis is adequate.

The BUN is a measure of the amount of waste substances (poisons) in a person's body. Urea, a by-product of protein, is normally excreted by the kidneys but when the kidneys do not work, urea builds up and causes the patient to have nausea and weakness. Dialysis removes the built up poisons. If patients skip dialysis treatments, the BUN

level will rise. A high BUN can also indicate internal bleeding.

Some patients admitted not doing PD on the proper schedule and even skipping some days. Tim, on CCPD, said, "I took a night off from dialysis and so lately my creatine is high" which means he is not getting enough dialysis.

Vern mentioned that he did not always dialyze when he should because of his girlfriend. "We were out and it wasn't convenient to do it." He wants to appear normal to her and the dialysis reminds everyone of his illness. He appears to be in denial about his illness. It is interesting to note that this girlfriend did not appear on the "Myers Important People" list and that the informant only assigned her a two on the closeness scale, which represents "neutral." So even though he wants to be normal for his girlfriend, she did not appear to mean that much to him.

Vern said, "I do CAPD four times a day. But sometimes I miss one. I usually use a 2.5% glucose dialysate bag but if I feel short of breath I will use a 4.25 bag. You can pull 1,000 cc of fluid with a 4.25 bag." Vern had a problem with using too many 4.25 bags and dried himself out too much. He got below his "dry weight" and this drop caused cramps. Michele said, "the 4.25 bags pull your eyeballs out," meaning that they really pull all the extra fluid out of a person. Some patients rely on using heavy

concentrations of glucose dialysate if they have missed doing PD exchanges or are heavily fluid overloaded. Rubin (1989) found that PD patients sometimes relied on a high-glucose dialysate, which pulls more fluid. This solution can sometimes result in glucose intolerance due to pancreas failure (Rubin 1989). In addition, patients who have had peritonitis, which results in peritoneal membrane thickening, often have to use higher levels of glucose to get an "adequate" dialysis (Rubin 1989). Higher levels of glucose in turn, can contribute to lack of appetite. This anorexia is also exacerbated because dialysis fluid in the abdomen causes the CAPD patient to feel "full." In addition, if the dialysis is not sufficient, uremia again contributes to lack of appetite.

Hematocrit and glucose.

Glucose levels are higher for the PD patients probably because a lot of PD patients are diabetic. There are advantages for diabetics to be on PD. Insulin can be injected into the dialysis bags instead of directly into the patient. The PD dialysate contains glucose and although it adds to the dietary calories of patients, patients can use lower levels of glucose dialysate if necessary. Diabetics have trouble with heparin, an anti-coagulant used for HD. Heparin can cause blindness in ESRD patients who are diabetic.

All ESRD patients have a lower hematocrit level than average, healthy people. Janean, a caregiver, said, "dialysis is a grey zone of living. Patients have an average hematocrit of about 20, which is half the normal hematocrit. Thus, they have half the normal energy too." Many of these patients complained to me of severe tiredness, so much so that they could not perform some household duties anymore. Tim said, "I can tell when my blood is down and I'm getting anemic. The symptoms are mostly tiredness, but I can also tell with regard to my sexuality."

Phosphorus and calcium. Phosphorus exists in all foods, and at particularly high levels in milk, cheese, dried beans, peas, nuts and liver (American Kidney Fund 1988). Phosphorous and calcium are balanced in the body. If one goes up the other goes down. So too much phosphorus in the body can cause calcium to leach out of the bones. A phosphorus level of four or above stimulates the parathyroid gland which starts the leaching process. Also, Dr. Edwards said that if the product of phosphorous & calcium is greater than 70, there is a high risk of tissue calcium deposits on soft tissue, such as the heart, brain, skin.

Laura said, "I avoid foods high in phosphorous--no dark pop. I don't eat phosphorous foods, but my family does." Valarie said, "I do eat some phosphorous foods but when my phosphorous is up I stop eating milk, eggs, cheese and oranges. Then I gradually eat them again." Cindy admitted

to the dietician that, "I eat cheese sandwiches and banana splits because I love them and they are good."

Because eating some phosphorous foods is unavoidable, patients have to take "phosphate binders," to bind the phosphorus in their intestines so that it is excreted and not absorbed into the blood. Some patients do not like the taste of phosphate binders. Often physicians prescribe Tums (a calcium antacid) which is somewhat more palatable. Phosphate binders cause constipation but patients are not allowed to drink prune juice since it has too much phosphorus in it.

Jessica was having a particularly hard time with high phosphorous levels and as a result she had sores on her body. Too much phosphorus in the body causes severe itching.

> I'm having trouble sleeping because of the sores, itching and nervousness. I also have no appetite. I took those phosphate binders but I think they are making me loose my hair, and making it thin and also causing the sores on my body, so I stopped taking them. (That only made things worse.) I stopped taking the Tums liquid and tried the tablets which are not as strong. I don't know what the medications are doing to my body. I don't want to put foreign things in my body. I'm not one for taking medications. I don't socialize anymore. I don't feel like being around anybody. I itch and I don't want anybody to see me like that. I'm bad. I eat what I want. I do the shopping and cooking. It's hard when you've got a husband to cook for. I feel tired all the time and don't have any ambition to do work, housework or to fix nice meals, but I wish I did.

Vern was having trouble taking his Tums. He is supposed to take five or six at a time as a phosphate

binder. But he often eats fast food and the Tums are "not handy (not with him)." Vern has also been told to eat Tums with his meals and not afterwards. Dr. Edwards said,

> Eating phosphate binders after meals does no good. This is making his calcium level borderline high. Someone told him that it was alright to take Tums other than at mealtimes. Why do people listen to each other and not to me?

Correlations between blood chemistries and other factors.

Pearson correlations between these patients' blood chemistries and other variables revealed:

1) The lower patients' BUN level, the more likely they are to say they are satisfied with life ($r=.36$, $p=.0081$). (Life satisfaction scale is scored so worst is highest).
2) The lower patients' BUN level, the better they would rate their overall health ($r=.31$, $p=.0273$). Overall health rating scale is scored so worst is highest. High BUN levels are accompanied by nausea, weakness and lethargy. Low BUN levels tend to make patients feel better.
3) The higher patients' density of relatives, the lower patients' BUN level ($r=-.31$, $p=.0257$).
4) The higher patients' total number of relatives, the lower patients' BUN level ($r=-.26$, $p=.0630$).

Although the last correlation is small and significant only at the .10 level, it points to a potentially interesting relationship between a particular health outcome and network structure. The density of relatives and BUN correlation is slightly higher (and more significant*) than the correlation between total number of relatives and BUN. Since it is not likely that BUN levels influence the number or density of relatives, it appears that these social network structural variables may influence this health outcome.

5) The higher patients' total network density the higher the amount of chloride found in blood serum (r=.31, p= .0240).

6) The higher the density of patients' relatives, the lower the blood serum phosphorus values (r=-.34, p=.0116).

7) The greater the number of people in patients' "important people" group, the higher the hematocrit levels (r=.30, p=.0309). The people listed as important are categorized as "strong" ties.

These correlations indicate there is some relationship between network structure (density) and phosphorous and chloride. It could be that those relations who know each other are also all aware that dialysis patients are supposed to avoid high-phosphorus foods. Perhaps their collective influence helps the patient avoid such foods.

The correlation between number of important people and hematocrit level could be due to the fact that those with a lower hematocrit need help from others and those others perform important functions, sometimes even doing everything for the patient.

Medical Questionnaire

A large part of the 95-item medical questionnaire was a group of items which reflected a combination of physical symptoms and mental attitude. This subscale consisted of items which could be answered with a yes or no. A yes indicated that the patient did have that physical pain, symptom or psychological problem. Total number of yes answers were added together, yielding a score for each informant. The more items chosen by a patient, the less healthy. Questions included having trouble sleeping, walking and standing, having various types of pain, feeling lonely, having trouble getting along with others, etc.

Table 26 shows the results of the medical scale variable. This range of this scale was from 0 (no symptoms) to 38 (yes to all symptoms). The average scores for patients on each type of dialysis was virtually the same, although PD patients had slightly more complaints than did HD patients (average 9.12 vs. 8.65). Women had about 9 complaints and men said they only had 7 (no significant difference). There was a slightly significant (.10 level) difference between races for this scale variable. White

patients had about eleven complaints and blacks had only about six.

Table 26. Medical subscale of physical and mental symptoms. Differences between white and black patients are slightly significant (at the .10 level). Overall mean = 8.88 (S.D. 7.06). Overall possible range of answers was from 0 to 38.

PD (S.D.)	HD (S.D.)	MALES (S.D.)	FEMALES (S.D.)	WHITE (S.D.)	BLACK (S.D.)
9.12 (5.73)	8.65 (8.29)	7.76 (6.04)	9.93 (7.86)	11.12 (7.85)	6.81 (5.63)
Range 0-20	Range 0-29	Range 0-29	Range 0-20	Range 0-29	Range 0-20

Rating of overall health. Another part of the medical questionnaire involved having the informants rate their overall health (Table 27). Although many patients often felt bad and complained of various physical ailments, a substantial proportion (46.2%) of them rated their overall health as "good." There were no differences between dialysis types (or race and gender categories) as to overall health rating and in fact, the counts for PD and HD patients for this question were exactly the same. Twelve patients in each dialysis category said they had good health. Ten in each said they had fair health and four said they had poor health. I think from patient comments that their own health rating was based on "health for a kidney patient," which is of course different from normal health. Patient estimation of health was grouped into two groups (good health or poor health). There were no significant differences between groups.

Table 27. Dialysis patients' self-rating of overall health. Sample size is only 52 because one patient died before she could complete this portion of the interview.

How Would You Rate Your Overall Health?	OVERALL DIALYSIS PATIENTS N = 52 Frequency (%)
Excellent	0
Good	24 (46.2%)
Fair	20 (38.5%)
Poor	8 (15.4%)

Table 28. Rating of overall health, grouped by race and gender categories. Percentages are of grouping variables. No significant differences.

	WHITE Freq. (%)	BLACK Freq. (%)	MALES Freq. (%)	FEMALES Freq. (%)
Good Health N=24 (46.2%)	11 (45.83)	13 (54.17)	10 (41.67)	14 (58.33)
Poor Health N=28 (53.8%)	12 (42.86)	16 (57.14	15 (53.57)	13 (46.43)

Satisfaction with health. The fact that so many patients said they were in good health probably helped raise the category of health satisfaction. Table 29 shows that nineteen patients (36.5%) said they were satisfied with their health. The one person who said he was completely satisfied with his health was a patient on HD. The patient who claimed to be very dissatisfied was also on HD. The "completely dissatisfied" category was split evenly between PD and HD. There were no significant differences on health satisfaction for race or sex (Table 30) although every

Table 29. Dialysis patients' self-rating of overall satisfaction with their health.

How Satisfied Are You With Your Health?	OVERALL DIALYSIS PATIENTS N = 52 Frequency (%)
Completely Satisfied	1 (1.9%)
Very Satisfied	9 (17.3%)
Satisfied	19 (36.5%)
Neutral	7 (13.5%)
Dissatisfied	11 (21.2%)
Very Dissatisfied	1 (1.9%)
Completely Dissatisfied	4 (7.7%)

Table 30. Satisfaction with health grouped by race and gender categories. No significant differences.

	WHITE Freq. (%)	BLACK Freq. (%)	MALES Freq. (%)	FEMALES Freq. (%)
SATISFIED N=29 (55.8%)	17 (58.62)	12 (41.38)	13 (44.83)	16 (55.17)
NOT SATISFIED N=23 (44.2%)	13 (56.52)	10 (43.48)	12 (52.17)	11 (47.83)

Table 31. Patients' self-reported life satisfaction. Table shows data overall, and by type of dialysis. Sample size is only 52 because one patient died before she could complete this portion of the interview.

RATING	OVERALL N=52 Frequency (%)	PERITONEAL N=26 Frequency (%)	HEMODIALYSIS N=26 Frequency (%)
Completely Satisfied	6 (11.5%)	2 (7.7%)	4 (15.4%)
Very Satisfied	9 (17.3%)	7 (26.9%)	2 (7.7%)
Satisfied	22 (42.3%)	11 (42.3%)	11 (42.3%)
Neutral	6 (11.5%)	3 (11.5%)	3 (11.5%)
Dissatisfied	6 (11.5%)	3 (11.5%)	3 (11.5%)
Very Dissatisfied	2 (3.8%)	0	2 (7.7%)
Completely Dissatisfied	1 (1.9%)	0	1 (3.8%)

Table 32. Satisfaction with life variable grouped by race and gender categories. No significant differences between racial or gender categories.

	WHITE Freq. (%)	BLACK Freq. (%)	MALES Freq. (%)	FEMALES Freq. (%)
Satisfied N=37 (71.2%)	16 (43.24)	21 (56.76)	18 (48.65)	19 (51.35)
Not Satisfied N=15 (28.8%)	9 (60.0)	6 (40.0)	7 (46.67)	8 (53.33)

patient category showed patient reported being more satisfied than unsatsfied with their health.

Satisfaction with life. Informants were also asked to rate their satisfaction with life, using the same scale as they used for their estimation of health satisfaction (Table 31). Most (42.3%) of both HD and PD populations were satisfied with their lives. The two groups are almost identical except that the HD patients had a slightly higher percentage of dissatisfaction with their lives than PD patients (again no differences for sex and race). About 12% of the HD patients were either very dissatisfied or completely dissatisfied, compared to zero for PD patients. Consequently, PD patients had a greater percentage in the completely satisfied and very satisfied categories with a total of 34.6%, while HD patients only totalled 23.1% for those two categories. Table 32 shows satisfaction with life as grouped by race and gender categories. There were no significant differences between blacks and whites and males and females according to life satisfaction.

Although most patients were satisfied with their lives, Misty was very dissatisfied with her life. When I asked her about having kidney disease she said,

> Emotionally I hate it. I hate my life now. The only good part about hemo is that I would be dead by now without the machine. But it hurts me to look at the machine. I want to smash it. About 90% of the time the treatment is painless; it is just a forced uncomfortableness. Kidney disease has made my life miserable. I can do no traveling. I'm too tired to go out or entertain. I have no sex life. I can't go

> shopping. I feel dependent on everyone. Sometimes after dialysis I feel terrible and go to bed. I am weak, with nausea and cramps. I once had this for 13 hours after a treatment and thought I might die.

Brandon said,

> when I found out I had to be on dialysis, I cried for two or three days constantly, because it looked scary. It was the fear of the unknown when I started, seeing my blood going through the machine. My doctor told me, that it was 80% mental and that would determine how I would be. I learned to deal with it.

But Brandon's situation was different. He had been a drug abuser since he was 14 years old and had not really had a normal adolescence. He said he was very depressed at first and continued his drug use until he finally accepted the fact that he had to live with dialysis.

> It was a big adjustment, having to come in. But I realized it was a life or death situation. It's time consuming but now it has made me more thankful for life. I appreciate life. If I had stayed a drug-abuser, I might have died on it. Now I have a social life, good relations with my girlfriend, parents and family and I'm learning how to live. I have a good relationship with God now. Since I'm not on drugs anymore my relationship with my parents is wonderful. They told me it was 'like a son that's been missing.' I appreciate life as I didn't before because I see how well my life is going now, compared to how it used to be. I do volunteer work for social services and try to help persuade kids not to choose drugs. I'm also learning to do macrame, which I like very much. I didn't have time for anything else but drugs before. I was very unhappy while I was on drugs and I didn't want to be on drugs but I was addicted. I used so long I just forgot about other things, like people.

So satisfaction with life seems to have a great deal to do with what life was like before ESRD. Brandon did not have a great life destroyed by ESRD. Misty, by contrast,

had a full life which came crashing to a halt because of ESRD.

Depression. Depression is a frequent problem of ESRD patients (Kutner et al. 1985; Burton et al. 1986; Israel 1986; Craven at al. 1987; Errico et al. 1990). Eric gave a good description of this. He said, "the mental part is the worst part of dialysis. In the denial state, you are always sick and depressed. Your mind controls your whole body."

Jessica said,

> I'm depressed because I feel like I'm in this problem all by myself, except when I'm here (at the dialysis center). I feel as if I'm a burden to my husband. I don't feel like he's sharing with me.

Jason said that having ESRD is very depressing, especially being around other patients.

> When you are in the hospital they put you in the wrong place. You are embarrassed to have other people see you do it (CAPD), even though they are on CAPD too. It's kinda depressing. You have a depression that becomes a part of your life. It stays with you. You don't realize it's there.

Some patients have been able to get through this kind of depression and adapt to their situations. Paul said,

> Your mind has a lot to do with how you feel and what you can do. You can make yourself feel depressed. You can either dwell on it and live in misery or not think about it and do the best you can. You have to put yourself in another world--not to ignore the one you're in totally, but somewhat so you don't dwell on it. You have to have determination and perseverance and a good wife. I don't worry about tomorrow. It doesn't exist. Today is the only day you can count on. Since I have this, I'm more conscious of my own mortality. I used to hunt but I don't have the heart to hunt anymore. Also

> the meat is loaded in potassium and phosphorous so I don't hunt because I can't eat the meat.

Valarie has adapted successfully also. "When I first got on dialysis I was bitter and depressed. Now it is a part of life, like brushing your teeth."

Shawn was very depressed at first but now his attitude is different. He told me, "ain't no use to worry. I've had to learn to live with it, so I'm not so depressed."

Tanya believes that "the key to dealing with dialysis is to stay active because active people won't be depressed." Laura said,

> "I don't worry about things. I don't need emotional support and I don't ever get depressed. If I can't do anything about it, I don't worry about it. I talk to God every day."

Table 33 shows the reported depression for the ESRD patients in this study. A majority of the patients (55.8%) said they were a little depressed during the past month. But quite a few patients (34.6%) said they never felt depressed. One PD patient reported being quite depressed, one HD patient was severely depressed and three HD patients reported being quite depressed. Chi-square analysis between the categories of depression and race and sex categories showed only significant*** differences in the category of gender and none for race. Most informants reported being a "little depressed now and then." Males seemed to report a bit less depression than females. There was a significant** correlation between depression and total

network density (r=.41, p=.0024). This means that patients with high density networks were likely to feel lower levels of depression. (The scale for depression went from 1=severely depressed to 5=never depressed.) Table 34 shows depression of informants, grouped by race and gender categories. Equal numbers (both 17) of black and white patients reported being depressed. Significantly* more females reported being depressed than did males (22 females and only 12 males).

Table 33. Self-evaluated depression of patients during the past month.

DEPRESSION (During The Past Month)	OVERALL PATIENT POPULATION N = 52 Frequency (%)	MALES Freq. (%)	FEMALES Freq. (%)
Severely Depressed	1 (1.9%)	0	1 (1.9%)
Very Depressed	0	0	0
Quite Depressed	4 (7.7%)	2 (3.85%)	2 (3.85%)
A Little Depressed	29 (55.8%)	10 (19.23%)	19 (36.54%)
Never Felt Depressed	18 (34.6%)	13 (25.0%)	5 (9.62%)

Another part of the large medical questionnaire used in this study was the assessment of problems with certain life situations. The percentage of each dialysis group that indicated a particular problem is shown in Table 35. I was surprised to see that in every category the PD patients said they had more problems than the HD patients. Possible

Table 34. Depression of informants, grouped by race and gender categories. Females were significanly* more depressed than males.

	WHITE Freq. (%)	BLACK Freq. (%)	MALES Freq. (%)	FEMALES Freq. (%)
Depressed N=34 (65.4%)	17 (50.0)	17 (50.0)	12 * 35.29)	22 (64.71)
Not Depressed N=18 (34.6%)	8 (44.44)	10 (55.56)	13 (72.22)	5 (27.78)

explanations for this finding will be discussed below. Although there were differences in each category, only two of them are statistically significant*: problems with social life and problems with sex life.

Table 35. Frequencies of problems with life situations reported by ESRD patients, overall and by dialysis mode. Percentages are for each column variable and are the percentage that patients claimed to have that problem. Only 52 patients completed this part of the study.

PROBLEMS WITH:	OVERALL N=52 Frequency (%)	PD N=26 Frequency (%)	HD N=26 Frequency (%)
Job or Work	19 (36.5%)	12 (46.2%)	7 (26.9%)
Looking After Home	25 (48.1%)	16 (61.5%)	9 (34.6%)
Social Life	21 (40.4%)	14 (53.8%) *	7 (26.9%)
Relations With Those at Home	8 (15.4%)	6 (23.1%)	2 (7.7%)
Sex Life	23 (44.2%)	16 (61.5%) *	7 (26.9%)
Interests and Hobbies	23 (44.2%)	14 (53.8%)	9 (34.6%)
Vacations	28 (53.8%)	15 (57.6%)	13 (50.0%)

Table 36. Frequencies of problems with life situations reported by ESRD patients, by race and sex categories. Percentages are for each column variable and are the percentage (out of 100%) that patients claimed to have that problem. Only 52 patients completed this part of the study.

PROBLEMS WITH:	WHITE N=25 Freq.(%)	BLACK N=27 Freq.(%)	MALES N=25 Freq.(%)	FEMALES N=27 Freq.(%)
Job or Work	11 (44%)	8 (29.6%)	12 (48%) #	7 (25.9%)
Looking After Home	15 (60%) #	10 (37.04%)	11 (44%)	14 (51.6%)
Social Life	15 (60%) **	6 (22.2%)	11 (44%)	10 (37.04%)
Relations With Those At Home	5 (9.62%)	3 (5.77%)	2 (3.85%)	6 (11.54%)
Sex Life	12 (48%)	11 (40.7%)	14 (56%)	9 (33.3%)
Vacations	12 (48%)	11 (40.7%)	14 (56%)	9 (33.3%)
Interests and Hobbies	14 (56%)	14 (51.9%)	15 (60%)	13 (48.5%)

significant at the .10 level

Problems with working. Not being able to work, or having to change jobs is of concern to many ESRD patients. Work may be threatening because it reminds the ESRD patients that they can't do the same things as before. (Chyatte 1979). Because of physical limitations, some people previously engaged in manual labor may have to give up working or severely limit what they do at work. In addition, hemodialysis schedules can make absenteeism a problem for employers. Generally, those who have a form of

home dialysis (CAPD or home HD) have the most flexibility and the highest vocational rehabilitation, in terms of full-time employment. About 70% of home dialysis patients go back to work, while only 40% of in-center patients do (Czaczkes and Kaplan DeNour 1978; Chyatte 1979). However, even for CAPD patients, it can be hard to find a relatively sterile place to perform an exchange. Some patients accept long term disability payments or state or federal assistance when they are first diagnosed with ESRD, but later feel well enough to return to work. However, full time employment can mean that things formerly paid for through assistance would now have to be paid personally. This can be too much of a financial burden on families, so the patient remains unemployed (Burton 1989).

Alex (1977) states that most employers do not know that patients do not feel well after (hemo) dialysis and have unreasonable expectations for patient work schedules. In addition, Raskin and Fishman (1976) report that 70% of dialysis patients (over all age groups) have severe headaches which also hamper their ability to work.

Only 6 patients in this study were employed, but 19 (36.5% of all informants) reported problems with work. Some patients indicated that they had problems with work because they <u>did not</u> have a job and wished to work. More PD patients in my study reported problems with work than did HD patients, although only one HD patient had a job at the time

of the interview. Chi-Square analysis indicated no significant differences between dialysis populations on this variable. Table 36 shows that whites and males reported more problems with work than did blacks or females. The difference between males and females was significant at the .10 level only.

Julie voiced her opinion about working and dialysis.

> One day you can physically handle things, the next you can't. That's why hemo patients don't work. It's not that they are lazy, it's that they are afraid that if they can do something one day and then they don't feel up to it another day, the boss will think they are lazy and then fire them.

She feels patients worry about whether they can do things and/or will always be able to do them.

Many patients said they could not do the type of job they did before they were diagnosed with ESRD. For example, Patrick, who had been a mechanic in his former job, said "you work constantly and are on your feet all the time. I am not able to work like that right now. Sometimes I feel ok, but sometimes not. Employers don't understand that."

There is also some prejudice towards dialysis patients. Vern is facing this so he is trying to appear normal at work. Vern said,

> my boss thinks my disease is dirty and she is prejudiced against me and is trying to get rid of me, to make me retire. So I don't dialyze at work. I do all of my exchanges in the evening when I get home from work, or in the morning before I leave.

Christina, now on HD, said, "you can't work and stay on hemodialysis. If you took too much time off, they would put you off the job."

Martin is trying to get a job similar to what he used to do but his potential employer is "sort of leery" of hiring someone who is on dialysis.

People with ESRD do have some physical limitations. Stanley has to do a lot of lifting and can only do it three and one-half hours a day. He has to find something else to occupy him for the rest of the eight hour shift. If he can not do that he has to go home and it takes away from his annual leave time. Sometimes limits are placed by others. Casey told me, the doctors don't want me to do anything." Mike said, "an insurance company would not even allow me a bank teller's job when I'm on hemo."

Jason talked about how it feels to still look healthy but be too ill to continue his former job. He thinks his former co-workers resent him.

> You don't look really sick, yet they know you are drawing retirement. Friends resent you drawing retirement. They don't see the kidney patient. They don't see the disease. They think you are using it as an excuse, especially CAPD patients who don't have the horrible arm disfigurement sometimes evident on hemo patients. During the first year you have to convince them that you <u>are</u> a kidney patient. On dialysis, either hemo or CAPD. You go into a room and come out. Especially with CAPD, you don't look any different at all.

I found that patients with a higher total number of friends were likely to report having more job problems

(r=-.35, p=.0104). (The job problems variable was coded so that one is having problems and two is not.) I do not know the reason for this but perhaps patients who are unemployed are able to spend more time with friends.

Problems with looking after the home. Dialysis patients often need help with housework and yardwork. Some patients can do nothing at all at home. Table 35 shows that 25 (48.1%) of these patients reported this kind of problem. There were no significant differences between HD and PD populations, although more PD patients (61.5% for PD vs. 34.6% HD) reported problems of this type. Peritoneal patients have to be careful not to lift objects that are too heavy and must be careful to keep their catheter clean. White patients (60%) reported having more problems with looking after the home than black patients (37%) did, but this was significant only at the .10 level. All the "problems with" variables in Tables 35 and 36 are coded the same as the previous one.

I found that those who reported no problems at home had higher number of relatives in the Myers network (r=.37, p=.0068) and higher number of relatives overall (r=.30, p=.0333). These correlations could mean that having no problems looking after the home has to do with having relatives (strong ties) around to help you get things done.

I also found that patients who had no problems with doing things around the home tended to have high

multiplexity (-.34, p=.0130), which in this study turned out to be a measure of frequency of interaction. Laura said, "I'm in a tight-knit family group. I can get everything I need in that group. I have cookouts with my family and I'm on the phone to them every day."

Problems with social life. Table 35 also shows the difference between PD and HD groups was significantly* different for problems with social life. Twice as many PD patients reported problems with their social lives as did HD patients (53.8% for PD vs. 26.9% for HD). Table 36 shows that problems with social life was a significant* problem for white patients. Sixty percent of white patients reported such problems, while only 22% of black patients reported them. Hemodialysis patients can do things on the day that they are not on dialysis. Perhaps they do not think of the days when they are not on dialysis as limiting their lives. Peritoneal patients must dialyze several times a day, every day. Some of the HD patients may look on dialysis as a social experience. Janean, a caregiver, said,

> in hemodialysis, the unit becomes their social network. Two patients who were otherwise good candidates, motivated and able for CAPD, tried it and were unable to stick with it because they lost their social network (fellow dialysis patients).

This is supported by the literature that people on HD are likely to be "social" types of people (i.e. those who like to be around others). In fact the literature says that some

people do not do well on CAPD after hemodialysis because their "friends, parties and enjoyment are found in in-center hemodialysis" (Moncrief 1989). However, I found that this is not true since no patient listed any fellow patients in their social networks. Errico et al. (1990:665), in a study of social support and depression, found only one of her patients listed a caregiver "as part of his support network."

Problems with relationships at home. Tables 35 and 36 show that this category represents the fewest problems for both dialysis groups and for racial and gender categories. Only two HD patients (7.7%) reported relationship problems at home. For PD patients, 23.1% reported these relationship problems. I think this has to do mostly with problems with spouses.

Problems with sex life. A number of studies have reported sexual problems as very prevalent in people with ESRD, some even after transplantation (Bertman 1978; Finkelstein and Steele 1978; Golden and Milne 1978: Kaplan De-Nour 1978; Procci et al. 1978; Oldenberg et al. 1988). Some of the contributing factors are: medication, feeling unattractive, spouse's fear of hurting the patient, the patient's fear of damaging a dialysis access site, lack of desire, impotence, fatigue, physical pain, frustration and anger at the spouse who is not on dialysis.

Burton (1989) found that HD patients reported significantly more sexual problems than did PD patients. However, Fuchs (1988) found that PD patients named sexual dysfunction as more stressful than did HD patients.

Sexual problems were, in fact, reported by 61.5% of the PD patients, while only 26.9% of the HD patients said they had problems with their sex lives (Table 35). This difference was significant*. There were no significant differences in sex life problems between racial and gender categories. However, categories of whites and males reported slightly more of such problems.

Some patients reported no problems with their sex lives. Susan, a PD patient, said, "there was no problem with sex, or how my husband felt about the catheter." Also, people who had already lost their sex lives reported no problems with it due to ESRD. These people were usually older people whose spouses had physical problems. Shawn said, "I don't have any of these type of problems because my wife has been sick for years." April said, "No, mercifully my husband has had diabetes for 10 years so there's none of that (sex)."

Other patients report that ESRD caused a significant problem with their sex lives. Brandon said, "my girlfriend is very supportive. When I started dialysis I had a low sex drive and she didn't understand. I took testosterone and things are better."

Some people were embarrassed to talk about this subject. Casey said,

> I don't worry about the other thing. (I asked him what he meant by "the other thing" and he said) "you know what I'm talking about." (He meant sexual activity.) Kidney disease takes that from you. If people say they are still having sex, they're lying. They might be thinking about it, but they're not doing it.

I discovered that the subject of sexuality was an important one which people sometimes spontaneously talked to me about. The literature on ESRD discusses this as a significant problem. I asked Ken, if ESRD gave him problems with his sex life, he laughed and said, "there ain't none of that going on anymore."

Jacob volunteered, "I was a hell-raiser and was with a different woman every night." One of the questions I asked informants was if there were anything they are physically not able to do that they did before they got their kidney failure. Jacob said,

> I don't have much endurance and can't play basketball as long as I used to. (Then he said) can I be frank? I can't have sex all night or every day anymore.

Jason said,

> my attitude about sex has changed. It used to be very important and now it is not important for me. But my wife does mind. Now I understand it (sex) more. Kidney disease gives you a low libido and infrequent erections. My wife and I have different bedtimes, which doesn't help matters. We are growing apart. My wife did not accept my peritoneal dialysis before. She thought I was getting HD and when I didn't, she was sort of in shock. I know my wife is revulsed by CAPD. I guess she is getting used to it now, but I can't forget the looks on her face, or her avoidance of

looking at my exit site. Even though she may accept it now, I still feel like a freak and I don't think that will never change. I've never thought of a divorce before, but now there is a high possibility. Not that I would want the divorce. I just expect that my wife will want it and find someone else to be with who can perform better sexually. I feel my wife would be better off with someone else. If I got divorced, I would stay single. I don't want to go through dialysis with another woman. I wouldn't want to go through that shame. There are emotional changes with everybody. By the time the spouse accepts it (CAPD), you still feel like a freak. It doesn't matter what they (the spouse) say. You become ashamed of your body. You withdraw from the family. Getting a transplant doesn't solve things. You still have scars even with a transplant. There is an embarrassment to making love. It is almost like an amputee but it's worse. With an amputee there is something gone that can't be replaced and no one expects it to be replaced. But you can get a new kidney, so people expect things to be different some day. My wife doesn't accept my dialysis because she thinks I will be ok someday. She doesn't accept that this is permanent for the rest of my life. Social workers make it worse because they encourage a transplant to my wife. I have a lot of bitterness about my kidney disease. This compounds my problems and makes my potassium problems worse.

Julie was also very frank about this sensitive subject.

She said,

it isn't romantic to say (when she realizes that her husband wants sex) 'wait dear, I have to do something with this bag.' When I get a signal that my husband wants sex, I just unobtrusively drop the bag over the side of the bed and try to keep the CAPD device covered with a sheet or something. My husband doesn't notice the scars on me anymore. My husband feels bad when he asks for sex.

Misty said,

I have no sex drive anymore. I'm too tired all the time and have sex with (her cohabitor of many years) only when he couldn't stand it anymore. Even then I could hardly wait for him to finish. I suspect he has a relationship with at least one other woman anyway. We are not that close anymore but we live together because we can't afford to live apart.

Inextricably tied to problems with sexuality is a difficulty with body image. This exists for both sexes.

Martin said,

> I've dated two women recently, but I'm self-conscious about the catheter. I guess I use my son as an excuse not to go out. I don't want to get involved and have to explain the catheter. So I say it wouldn't be good for my son if I were involved with a woman.

Rick said, "the catheter is uncomfortable in a social sense but not physically uncomfortable. It takes away from the aesthetics of my body." This informant exercises and takes care of his body.

Jenny said, "I'm used to the catheter so it's a part of me. My friend had a bit of trouble getting used to it but he eventually did." Misty said

> I would not like PD and wouldn't like two or three liters of fluid in my gut. I also wouldn't like a catheter coming out of my abdomen. I would have a hard time dealing with that.

Problems with interests and hobbies. Many patients said they did not have time for hobbies. However, some people are able to continue with the things they liked to do. In this sample, 23 patients (44.2%) indicated they had problems with hobbies (Table 35). For HD patients, this percentage is 34.6% and for PD patients it is higher, 53.8%. The amount of problems with interests and hobbies was virtually identical over racial and gender categories (Table 36).

Problems with vacations and travel. Many patients mentioned that they did not go places anymore. Over half of these patients overall (53.8%) said they had trouble with vacations and traveling. Hemodialysis patients (50%) said they could not go places because they would have to be back to their dialysis center for dialysis. It is possible to set up appointments for dialysis in other cities when traveling but it can be a problem if it is the busy traveling season, if the place where a patient wants to go may has no room, (or has a policy against dialyzing transient patients). The peritoneal patients (57.6% of them) also had trouble with vacations and traveling. The PD patients do not have to arrange time on a hemodialysis machine, but they must either take their PD supplies with them, or arrange for them to be delivered to their destination. Many PD patients felt that this was "too much junk" to carry around or too much trouble, although I did hear stories of one patient who had PD supplies delivered to Disney World. Perhaps many PD patients have not actually tried to travel and just think it would be too difficult. At any rate, long-distance travel on either type of dialysis must be planned out weeks in advance. Sometimes events happen which people do not have that much time to plan. Several patients mentioned that they were not able to go to the funerals of relatives because of HD. Dillan was unable to go to his uncle's funeral in another state. Julie said,

"my mother died while I was on a dialysis machine. If I had been on CAPD I would have called up and ordered my supplies and I could have been there."

Psychological Evaluators

Locus of control. The construct, "Locus of Control" has been used in a lot of research. (See Wallston et al. 1978, and Wallston and Wallston 1981 for comprehensive reviews of research with this construct and mixed results with using it). Some of these studies have involved dialysis patients (Wenerowicz et al. 1978; Poll and Kaplan De-Nour 1980; Zetin et al. 1981; and Nissenson et al. 1984). The idea of "locus of control" was developed by Rotter (1966) and it refers to whether a person believes that he or she is in control of life or that other forces are in control. The idea behind locus of control studies is that people who believe they are in control will try to do something about their life and health situation. Those who believe others are in control will give up and not try to change things. This has strong implications for compliance with health regimens: those who believe that others control one's life should exhibit low compliance.

Rotter classified people as either "internals" or "externals," depending upon whom they thought controlled their lives. Building on Rotter's scale, Wallston et al. (1978) developed the Health Locus of Control Scale, a

unidimensional Likert scale, designed to yield a single score. However, Levinson (1974) described control by others as a two-dimensional entity. One dimension was control by "powerful others" and one was control by "chance." Wallston et al. (1978) then developed the Multidimensional Health Locus of Control Scale, a six-point Likert scale which addressed three dimensions of control: internality (IHLC), powerful others (PHLC) and chance (CHLC). At about the same time Lau and Ware (1981) developed the Lau-Ware Locus of Control Scale, a seven-point Likert scale with four dimensions. Nissenson et al. (1986) used the Multidimensional Health Locus of Control Scale in their study of ESRD patients, so I chose the MHLC scale also.

Table 37 shows the averages overall and for each dialysis population on the three dimensions of MLOC. In general, the PD patients have higher values for all three dimensions. This was also found in Nissenson et al. (1986). There is a highly significant*** difference between PD and HD populations on the dimension of chance health locus of control, but no other significant differences between PD and HD patients. Nissenson's group found no significant differences between HD and PD populations. In addition, I also looked at MLOC by both racial and sex groups and found no significant differences between HD and PD groups.

Table 37. Mean values of three dimensions of Multidimensional Health Locus of Control, overall and by type of dialysis.

TYPES OF HEALTH LOCUS OF CONTROL	OVERALL (S.D.)	PERITONEAL (S.D.)	HEMODIALYSIS (S.D.)
INTERNAL HLC	2.62 (.95)	2.63 (.94)	2.61 (.98)
POWERFUL OTHERS HLC	2.93 (1.16)	3.19 (1.32)	2.68 (.93)
CHANCE HLC	3.71 (1.08)	4.22 (1.00) ***	3.23 (.94)

p-value .0005

It is often said that PD patients tend to be highly motivated, want personal independence and freedom, and are intelligent enough to follow the directions for PD. They need to have a knowledge of ESRD and its symptoms because the patient has to make decisions about the timing of dialysis, diet and fluid intake (Moncrief 1989). It is also said that people who are almost "obsessive-compulsive" will do well on PD because this mode of dialysis requires daily charting of weight and blood pressure, keeping track of where and when to do dialysis and meticulous attention to sterile exchange procedures. Additionally, people who are non-compliant on hemodialysis are not good candidates for PD (Kaplan DeNour and Czaczkes 1972; Burton et al. 1989).

In many dialysis centers, PD patients are selected for this type of dialysis because they are thought to be more internally driven to take care of themselves. Sometimes physicians think that blacks in general do not have the intelligence or the motivation to successfully do PD. Also,

people on PD need to have a sterile area for exchanges and a telephone for consultations with caregivers. So, often blacks are not selected for PD because the above reasons. Thus, the same theories driving the MHLC instrument drive the caregivers' decision to allow patients to try PD. Theoretically, the patients currently on HD and PD should have similar answers as the other members of their dialysis group to the questions on the MHLC and should think and behave similarly.

I used multidimensional scaling (MDS) to visually represent the MHLC, and to see if HD and PD patients would be grouped together. First, I created an informant-by-informant proximity matrix for these data. Each informant's answers were compared to each other. Then, I ran a two-dimensional MDS on this proximity matrix to create Figure 1. The PD and HD patients appear randomly across the page, instead of being in groups as one might expect. Thus, there appears to be no pattern of groupings between HD and PD patients. This result was confirmed by cluster analysis. The "stress" on this figure was .216. Stress is just the measure of the difficulty of mapping items based on their "distance" from each other. Stress values over .20 are indicative of randomness in the data rather than pattern. Scott (1991:164) charitably reports that "stress values approaching 20 percent are 'poor'." Thus the MDS for these data is not a good fit, which means that there is too much

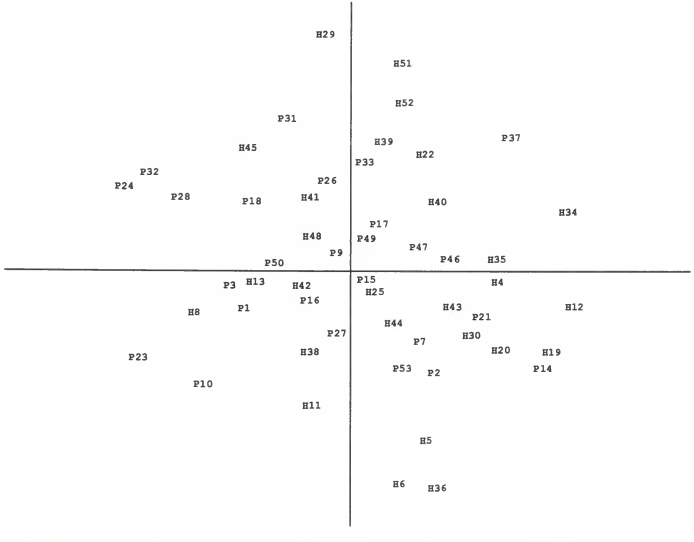

Figure 1. Multidimensional Scaling Plot of the responses of HD and PD patients to the Multidimensional Locus of Control.

variability in the data. This was also confirmed by factor analysis. In practical terms, this means that HD people did not answer the questions asked them like others in their group, and not differently from the way PD people answered the questions. This means there are really no differences overall in HD and PD groups as to whether or not they feel they are in control of life or whether or not they feel they are responsible for their care.

Profile of mood states. People who have ESRD have a lot of feelings to deal with. They are depressed, angry, bitter and unhappy sometimes and at other times they are happy and accepting of their illness.

One way of measuring an individual's feelings is the Profile of Mood States Instrument (POMS). This instrument has been used extensively with healthy and sick populations. See McNair et al. (1992) for a review of studies using the POMS. Nissenson et al. (1986) used this instrument and I also administered it to the patients in this study. The POMS is a 65-item questionnaire which evaluates patients' negative and positive moods using a 5-point Likert scale. Patients were asked if they had a particular feeling "not at all," up to "extremely," with three choices between those two answers. The POMS measures 6 factors, including tension, depression, anger-hostility, vigor, fatigue, and confusion. Most of the moods in this instrument are negative. The POMS can be scored in two ways. First,

scores can be compiled for each factor and used separately or a single index can be created. The single index is created by subtracting the vigor score from all the other scores. In this research, the single index was used, except that positive and negative feelings were made into two indexes, one positive (called POMSPOS) and one negative (called POMSNEG). Factor analysis on these data confirmed the negative and positive dimensions of POMS and confirmed my choice of feelings to be put in the positive or negative groups.

Table 38. Averages for positive (POMSPOS) and negative (POMSNEG) feelings in Profile of Mood States instrument, overall and by dialysis type. There were no significant differences.

	OVERALL (S.D.)	PERITONEAL (S.D.)	HEMODIALYSIS (S.D.)
POMSPOS Range 7-62	34.38 (12.81)	32.77 (11.53)	35.93 (13.98)
POMSNEG Range 0-168	41.04 (41.44)	36.42 (32.98)	45.58 (49.44)

I expected that, because of the morbidity of the hemodialysis treatment, HD patients would have a greater amount of negative feelings and mood states than would patients on PD. Table 38 shows the averages overall and by dialysis mode for this POMS instrument. Although not statistically significant, HD patients have a higher score on both the positive and negative indexes. This means HD patients had a wider array of feelings than did PD patients. The greater variability in their answers also is exhibited

in Figure 2, which is a multidimensional scaling of the POMS (done the same way that the MDS for the MLOC was done). Again, there are no clear groupings of PD and HD patients. This was also confirmed by factor analysis.

Some patients' positive attitude has to do with accepting dialysis. Peter said, "if you don't worry about it {ESRD} you will be ok, if you start worrying about it you don't last long." Tiffany has been on dialysis a long time but said,

> When I had to go on dialysis I had never even heard of it before and I didn't accept it. I finally got the idea that it was something I had to do so I don't worry about it.

Tim said, "you have to play with the hand you're dealt. Attitude is everything." Shannon exhibited a common fatalistic view of illness, that "sickness is for everybody. Everybody gets it a different way." Heather said,

> a person's attitude has to be good about being on dialysis and you have to accept that you have to do it. You know when you come in here there's only one way to get out {she meant death}.

What other factors are having an effect on the feelings of HD and PD patients? I looked some network and sociodemographic variables to see if there were any correlations between them and patients' feelings. I found:

1) Those patients who say they belong to a formal religious group tend to have less negative feelings ($r=-.30$, $p=.0245$).

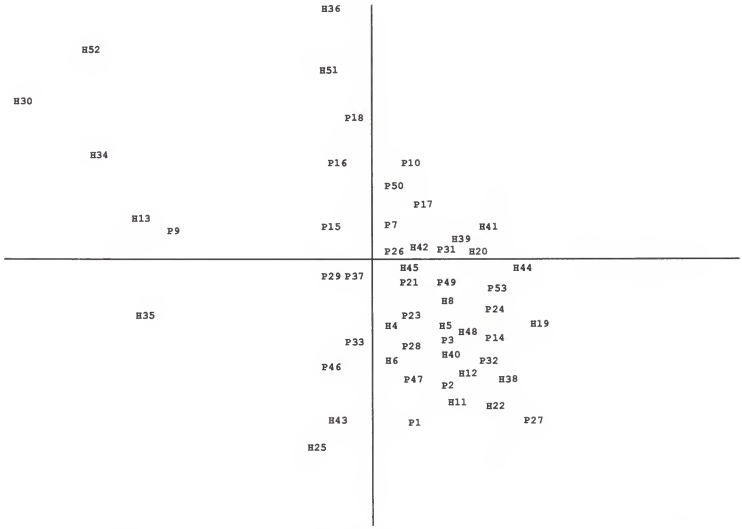

Figure 2. Multidimensional Scaling Plot of the responses of HD and PD patients to the Profile of Mood States.

2) White patients tend to have less negative feelings (r=-.24, p=.0829).

3) Patients who have a higher total number of relatives tend to have less negative feelings (r=-.28, p=.0434).

4) Patients who have a higher total network density tend to have less negative feelings (r=-.25, p=.0731).

5) Patients have more positive feelings the younger they start on dialysis (r=-.25, p=.0699).

6) Patients have more positive feelings the longer they have been on dialysis (r=.27, p=.0539).

Although these correlations are small and of low significance, they seem to indicate that church membership, race, total number of relatives in one's social network and total network density have something to do with lowering patients' negative feelings. There seems to be a trend that more positive moods are associated with being younger when one is diagnosed with ESRD and being on dialysis for a longer period of time. This seems very strange and impossible. However, this could be a result of patient adaptation to being on dialysis as time passes.

To further illuminate things, I performed separate correlations on the data by dialysis type, race and sex.

I found these correlations in the subgroupings:

1) For HD patients, there was a tendency to have more positive feelings the younger a patient started on dialysis (r=-.45, p=.0186).

2) For blacks, there was also the tendency to have more positive feelings the younger a patient started on dialysis (r=-.40, p=.0329).

3) For whites, there was a tendency to have more negative feelings the younger a patient started on dialysis (r=-.41, p=.0421).

4) Also for whites, patients had more positive feelings the longer they had been diagnosed with ESRD (r=.41, p=.0394).

5) Specifically for females, patients had more positive feelings the longer they had been diagnosed with ESRD (r=.53, p=.0039).

These subgroup correlations are larger and have higher levels of significance than the ungrouped correlations reported earlier. In general, they indicate that those who are black and on HD tend to have more positive feelings the younger they started dialysis. There is a strong correlation between having positive feelings the longer one has had ESRD but it this is only for white females. Apparently white females have somehow adapted to being an ESRD patient better than any other group I examined.

Table 39 shows POMSPOS and POMSNEG values for subcategories of race and sex. Whites have more negative

feelings than do blacks (51.48 vs. 31.71), but only at the .10 significance level. Blacks have, on average, more positive feelings than do whites (35.93 vs. 33.56), but this is not significantly different. In general, males have both more positive feelings and more negative feelings than females (not significant).

Table 39. Averages for positive (POMSPOS) and negative (POMSNEG) feelings in Profile of Mood States instrument, overall and by race and sex categories. There is a .10 level significance between black and white for the variable POMSNEG.

	BLACK (S.D.)	WHITE (S.D.)	MALE (S.D.)	FEMALE (S.D.)
POMSPOS	35.93 (13.99)	33.56 (12.05)	35.68 (13.39)	33.21 (12.40)
POMSNEG	31.71 (35.25)	51.48 (45.90)	41.84 (45.83)	40.32 (37.93)

Cantril scale. I asked informants to look at the Cantril "Ladder of Life" (Cantril 1965) which has ten levels. Zero is the bottom level, indicating the worst possible life that the informants could imagine, and ten is the highest level, the best life they could imagine. Informants were to say where they thought they were on the ladder at present, five years ago, and where they thought they would be five years in the future. Most people (58.5%) thought they were pretty well off five years ago. This percentage represents those patients who picked seven or above on the Cantril scale of where they were five years ago. Sixty-six percent picked seven or above for where they

think they are at present. Similarly, 66% picked seven or above for the future, and 42% of those patients chose ten for the future. Other studies indicate that ESRD patients have a dim conception of the future (Czaczkes and Kaplan De Nour 1978). It was possible for a person to drop or raise the level choice by nine (for example if they thought they were a ten now but would be a zero in the future). The range in these data was -9.0 to +8.0, meaning that someone dropped as low as nine levels and no one thought they would improve more than eight levels. The overall mean for this variable was 0.87 (standard deviation 3.11) with no significant differences between HD and PD groups.

Feelings of dependency. ESRD, especially HD patients, have often been characterized as dependent on others. However, only twenty informants (39.2%) said they thought they were dependent on others. These patients were from both HD and PD groups and there was no significant difference between them. I did not discover a profile of a dependent person. Feelings of dependency were found across race, sex and dialysis categories.

Dependency ranged from feeling "dependent on everyone" to wanting "to do for myself." Tim voiced the opinion of a lot of patients and said, "anything I can do for myself, I don't want anyone to do it." Paul felt dependent upon his wife and was upset about his overall condition of dependency. He said,

> I don't like being dependent on others. People worry about me doing too much. I feel especially dependent on my wife. She's had to do everything. I'm upset that I have to ask her help with physical stuff since there is no neighbor for a mile. I used to pay the bills and now I can't because it's too much for me emotionally and I can't stand it. In a traditional sense, my life is useless. I am a burden on society, not a productive person.

Julie said,

> I feel dependent on a vast support system, encompassing a variety of dimensions: physical, emotional, health, financial. I feel dependent on my husband, friends, doctors, nurses, the supplies company, the pharmacy, and social security. I learned that I can't lean on people anymore, they love me too much. When I depend on others, they feel so responsible for my care and welfare that they deprive themselves of things or life satisfaction. This makes me feel bad so I would rather not lean on others.

But in general her dependency did not bother her and she accepted it as part of having ESRD.

Comparison with Healthy Populations

Some of the instruments used in this research have been used previously for healthy populations. The results of the study using different network generators (Bernard et al. 1990) is shown in Table 40. The Jacksonville and Mexico City populations were both composed of healthy individuals. For each network generator used, the dialysis patient population has a much smaller social network. The healthy Jacksonville informants had at least twice as many network members as did the dialysis patients in this study. The dialysis patients' networks are very constricted. There were no significant differences in these network generators according to dialysis type, gender or race. Perhaps the

Table 40. Comparison of social network generators in this and previous studies.

NETWORK	DIALYSIS (S.D.)	JACKSONVILLE (S.D.)	MEXICO CITY (S.D.)
Question on confidential matters (Intimate Network)	1.68 (2.29)	6.88 (4.89)	2.95 (2.66)
Fischer Questions (Instrumental Network)	10.53 (5.66)	21.82 (16.66)	10.05 (6.45)
Freeman Phone Book Study (Global network)	3.70 (4.18)	11.51 (11.32)	4.20 (7.66)
COLUMN TOTALS	15.91	40.21	17.20

differences are due to employment. During the course of a workday, one runs into many people. Dialysis patients, for the most part, are not employed. This would naturally constrict their network size. It appears that dialysis patients, and maybe other chronically ill populations also, are at a disadvantage because they don't have as many network members to call on as healthy people.

The mean network sizes for each network generator are more like the values for Mexico City. At that time of their study, Bernard's group could not explain the differences between Jacksonville and Mexico City results. I cannot explain these differences either. More research on other chronically ill populations would indicate whether this is a fluke or some regular pattern. But there are some hints

that those who are sick have a smaller social network than healthy individuals. For example, Pattison et al. (1975) looked at several studies of network size with healthy informants and compared them to his neurotic population. For their informants, Pattison's group found an intimate network size of 10-12 people. He contrasted his findings with those of his normal group who had an intimate network size of 20-30. He also examined Boissevain 's (1974) research which also found a size of 30 individuals in the intimate network.

Fischer (1982) found, using their instrument, that the average instrumental network size is about 18 members. Since this present study uses a modification of the Fischer instrument, the results in this study should be similar to his findings. Comparing the data in the present study with Fischer's data show that dialysis patients only have 12 people to count on for instrumental needs. Even adding the intimate network and the instrumental network only adds another person. Thus, it appears even more likely that chronically ill people really do have smaller social networks than healthy people.

Bernard et al. (1990) also counted the numbers of relatives, friends and acquaintances in the healthy Jacksonville and Mexico City populations. The counts of friends, relatives and acquaintances were totaled from all four network generators they used. Unfortunately, some of

their data in the last network generator was lost and they had to estimate the numbers of friends, relatives and acquaintances in that network generator by using percentages discovered in the other network generators. In the present study, I only used three of their network generators. Therefore, Table 41 compares the same three network generators they used and which were used in this study, except that the dialysis data also includes the totals from the Myers network generator. The numbers in parentheses were the estimates. It would appear that dialysis patients had more relatives in their networks than Jacksonville or Mexico City residents. However, recall that the dialysis totals also have an additional network generator. Therefore, dialysis patients again have smaller numbers of social network members than healthy populations. This is particularly evident in the number of friends and acquaintances found in both the Jacksonville and Mexico City populations (even subtracting the estimates).

Table 41. Comparison of counts of relatives, friends and acquaintances between dialysis patients, healthy Jacksonville informants and healthy Mexico City informants. Numbers in parenthesis indicate estimates added due to missing data. These data were estimated using partially retrieved data. Dialysis data includes Myers network generator.

	DIALYSIS PATIENTS	JACKSONVILLE HEALTHY	MEXICO CITY HEALTHY
RELATIVES	10.79	13.84 (+3)	6.33
FRIENDS	5.21	42.86 (+28)	8.54
ACQUAINTANCES	3.75	71.64 (+69)	3.53

Multiple Regression Analysis

Multiple regressions were performed with these data to see if social network variables could predict health outcomes. I did a stepwise regression with social network variables only (the Net Model), and then with sociodemographic variables and network variables (the Full Model). The Net Model consisted of these variables: 1) number of strong ties, 2) total network size 3) number of relatives, 4) number of friends, 5) number of acquaintances 6) total network density, 7) multiplexity (actually a measure of interaction time, 8) satisfaction with advice from network, 9) satisfaction with help from network, 10) satisfaction with emotional support from network, 11) percent of reciprocity given to patient, 12) percent of equal reciprocity, 13) percent of reciprocity given by the patient, 14) length of time network relationships have existed, 15) frequency of contact with network members, and 16) emotional intensity (closeness) between network members and informants. The Full Model consisted of the above variables plus the addition of 1) race (white=1, black=0), 2) gender (males=1, females=0) 3) type of dialysis (PD=1, HD=0), 4) years with ESRD 5) length of time on current dialysis, 6) age at onset of ESRD, 7) church membership (member=1, nonmember=0), and 8) church attendance (attend=1, nonattendance=0). All variables used in these regressions were either interval, ratio or dummy variables, which are

all appropriate for use in multiple regression. There were more network variables which could have been used in these analyses but they were present within the variables used. For example, I did not use density of relatives because it is partially represented in the variable "total network density." I also did not use other socioeconomic variables (i.e. education and income) because there were no significant differences in those variables within this population of informants. Since R-squares can be inflated by having many variables, I tried to use the most parsimonious group of variables, while still using the variables which might help predict health outcomes. For each health outcome, the identical two models were used (the Net Model and the Full Model). Then the entire regressions were performed again for the category of race. The results are presented in Tables 42-50.

In general the models were all significant, some very much so. Regressions with social network variables alone do not produce very large R-square values, except for that of depression (R-square = .43) and life satisfaction (R-square = .48). There are some striking differences in both the Net Model and Full Model regressions, particularly for race. For white patients, network model regressions predicting BUN (R-square = .60), phosphorus (R-square = .70), negative moods (POMSNEG R-square = .66), and health satisfaction (R-square = .54) are particularly high. However, there is

usually much improvement in the model with the addition of sociodemographic variables. In the Full Model there were several very predictive models: prediction of 1) health satisfaction (R-square = .55 overall, .62 for blacks, .54 for whites), 2) life satisfaction (R-square = .56 overall, .55 for blacks and .89 for whites), 3) depression (R-square = .54 overall, .79 for blacks and .76 for whites), 4) patient weight (R-square = .86 for blacks), 5) medical scale (R-square =.64 for whites), 6) potassium (R-square =.71 for whites, .55 for blacks), and 7) phosphorus (R-square .70 for whites). The variables frequency of contact, length of time in relationship, and total network density appeared most often in these regressions. Intensity of relation, multiplexity and amount of advice received also appeared frequently. Looking at the regression models in Tables 42-50, one gets the distinct impression that social network variables, and thus social structure, can be useful in predicting health outcomes. If social network information were retrieved from dialysis patients (similar to this research), perhaps patient health outcomes could be predicted and patient quality of life enhanced.

Table 42. Regression models for dependent variable--weight of patients.

DEPENDENT VARIABLE: WEIGHT	PREDICTOR VARIABLES	PARAMETER ESTIMATES	PARTIAL R-SQUARE
NET MODEL:	1) Frequency of contact	-.002	.07
R-SQ. = .12	2) Relation intensity	-.227	.05
p = .0452			
FULL MODEL:	1) Frequency of contact	-.002	.07
R-SQ. = .32	2) Gender (M=1; F=0)	.493	.09
p = .0021	3) Relation Intensity	-.249	.07
	4) Race (W=1; B=0)	.304	.04
	5) Church member	.291	.04
FOR BLACKS NET MODEL: R-SQ.=.17 p = .0282	1) Frequency of contact	-0.004	.17
FOR BLACKS FULL MODEL:	1) Frequency of contact	-0.003	.17
R-SQ. = .86	2) Gender (M=1; F=0)	.960	.14
p = .0001	3) Emotional support	.007	.08
	4) Help	-0.003	.10
	5) Advice	-0.002	.11
	6) Relation intensity	-0.529	.07
	7) Age at onset of ESRD	0.012	.04
	8) Number of acquaintances	-0.141	.05
	9) Church member	.516	.04
	10) Network gives more	.007	.05
FOR WHITES NET MODEL: R-SQ. = .29 p = .0056	1) Time in relationship	-0.043	.29
FOR WHITES FULL MODEL:	1) Time in relationship	-0.045	.29
R-SQ. = .39	2) Church member	.392	.10
p = .0047			

Table 43. Regression models for dependent variable--Blood/Urea/Nitrogen (BUN) (low levels of BUN are desirable.)

DEPENDENT VARIABLE: Blood/Urea/ Nitrogen (BUN)	PREDICTOR VARIABLES	PARAMETER ESTIMATES	PARTIAL R-SQUARE
NET MODEL: R-SQ.= .11 p = .0166	1) Advice of Network	-0.049	.11
FULL MODEL: R-SQ.= .38 p = .0003	1) Advice of Network 2) Gender (M=1; F=2) 3) Years with ESRD 4) Acquaintances 5) Reciprocity in favor of patient	-0.087 14.023 1.198 .867 -.141	.11 .11 .08 .04 .04
FOR BLACKS NET MODEL: R-SQ. = .30 p= .0307	1) Total network density 2) Number of acquaintances 3) Equal reciprocity	-0.720 -4.069 -0.126	.09 .14 .07
FOR BLACKS FULL MODEL: R-SQ. = .20 p = .0615	1) Gender (M=1; F=0) 2) Age at onset of ESRD	11.445 0.345	.11 .09
FOR WHITES NET MODEL: R-SQ. = .60 p = .0001 FULL MODEL: Identical to NET MODEL	1) Time in relationship 2) Help	-1.556 -0.057	.24 .36

Table 44. Regression models for dependent variable--Phosphorus (low levels desirable).

DEPENDENT VARIABLE: PHOSPHORUS	PREDICTOR VARIABLES	PARAMETER ESTIMATES	PARTIAL R-SQUARE
NET MODEL: R-SQ.= .07 p = .0539	1) Time in relationship	-0.060	.07
FULL MODEL: R-SQ. = .38 p = .0003	1) Attend church 2) Time in relationship 3) Race (W=1; B=0) 4) Total network density 5) Gender (M=1; F=2)	-0.632 -0.065 1.104 0.021 0.725	.15 .06 .05 .07 .05
FOR BLACKS NET MODEL: R-SQ. = .17 p = .0297	1) Number of acquaintances	-0.262	.17
FOR BLACKS FULL MODEL: R-SQ. = .31 p = .0097	1) Number of acquaintances 2) Gender (M=1; F=0)	-0.270 1.003	.17 .14
FOR WHITES NET MODEL: R-SQ. = .42 p = .0025	1) Time in relationship 2) Total network density	-0.144 0.025	.26 .16
FOR WHITES FULL MODEL: R-SQ. = .70 p = .0005	1) Time in relationship 2) Total network density 3) Age at onset of ESRD 4) Number of friends 5) Equal reciprocity 6) Multiplexity	-0.300 .020 .070 -0.133 .021 -0.012	.26 .16 .09 .07 .07 .06

Table 45. Regression models for dependent variable--Potassium (low levels desirable).

DEPENDENT VARIABLE: POTASSIUM	PREDICTOR VARIABLES	PARAMETER ESTIMATES	PARTIAL R-SQUARE
NET MODEL: R-SQ.= .05 p = .0995	1) Total network density	-0.006	.05
FULL MODEL: R-SQ.= .48 p = .0001	1) Type of dialysis 2) Race (M=1; W=0) 3) Advice of Network 4) Gender (M=1; F=0)	-0.636 .449 .001 .325	.21 .09 .10 .08
FOR BLACKS NET MODEL: R-SQ. = .13 p = .0627	1) Number of strong ties	.039	.13
FOR BLACKS FULL MODEL: R-SQ. = .55 p= .0001	1) Type of dialysis 2) Advice 3) Gender (M=1; F=0) 4) Multiplexity	-0.649 0.002 .313 -0.006	.33 .10 .07 .05
FOR WHITES NET MODEL:	No variable met .15 sign. level.		
FOR WHITES FULL MODEL: R-SQ. = .71 p = .0001	1) Type of dialysis 2) Advice 3) Time on current dialysis mode 4) Reciprocity in favor of patient 5) Age at onset of ESRD 6) Frequency of contact 7) Number of acquaintances	-0.902 0.003 -0.005 -0.016 0.002 -0.029	.19 .10 .15 .07 .07 .06 .06

Table 46. Regression models for dependent variable--Medical Scale (subscale of informant's mental and physical ailments) (low levels desirable).

DEPENDENT VARIABLE: MEDICAL SCALE	PREDICTOR VARIABLES	PARAMETER ESTIMATES	PARTIAL R-SQUARE
NET MODEL: R-SQ.= .16 p = .0336	1) Number of relatives	-0.268	.07
	2) Relation intensity	-3.117	.04
	3) Frequency of contact	-0.017	.05
FULL MODEL: R-SQ.= .24 p = .0099	1) Race (W=1; B=0)	4.306	.09
	2) Number of relatives	-0.250	.05
	3) Relation intensity	-2.234	.06
	4) Frequency of contact	-0.021	.04
FOR BLACKS NET MODEL:	No variable met the .15 level of significance.		
FOR BLACKS FULL MODEL: R-SQ. =.24 p = .0376	1) Type of dialysis	5.598	.16
	2) Equal reciprocity	-0.050	.08
FOR WHITES NET MODEL: R-SQ.= .23 p = .0597	1) Time in relationship	-0.350	.14
	2) Frequency of contact	-0.020	.08
FOR WHITES FULL MODEL: R-SQ. = .64 p =.0009	1) Time in relationship	-0.709	.14
	2) Type of dialysis	-5.127	.23
	3) Gender (M=1; F=0)	-7.914	.13
	4) Attend church	-6.701	.07
	5) Emotional support	-0.015	.06

Table 47. Regression models for dependent variable--Depression (low levels desirable).

DEPENDENT VARIABLE: DEPRESSION	PREDICTOR VARIABLES	PARAMETER ESTIMATES	PARTIAL R-SQUARE
NET MODEL:	1) Total network density	.011	.17
R-SQ.= .43	2) Time in relationship	.029	.08
p = .0115	3) Advice	.002	.06
	4) Frequency of contact	.002	.05
	5) Number of Acquaintances	-.044	.05
	6) Multiplexity	.005	.03
FULL MODEL:	1) Total network density	.016	.17
R-SQ.= .54	2) Gender (M=1; F=0)	.586	.12
p = .0001	3) Time in relationship	.042	.12
	4) Advice	.002	.05
	5) Years on current dialysis mode	.056	.03
	6) Frequency of contact	.001	.03
	7) Multiplexity	.005	.03

Table 47--continued.

DEPENDENT VARIABLE: DEPRESSION	PREDICTOR VARIABLES	PARAMETER ESTIMATES	PARTIAL R-SQUARE
FOR BLACKS NET MODEL: R-SQ. = .31 p = .0024	1) Reciprocity given by patient	-0.011	.31
FOR BLACKS FULL MODEL: R-SQ. = .79 p= .0001	1) Gender (M=1; F=0)	.641	.35
	2) Reciprocity given by patient	-0.012	.30
	3) Help	.001	.05
	4) Age at onset of ESRD	.009	.04
	5) Type of dialysis	-0.260	.05
FOR WHITES NET MODEL: R-SQ. = .59 p = .0009	1) Total network density	.022	.40
	2) Advice	.003	.09
	3) Time in relationship	.042	.06
	4) Multiplexity	.006	.04
FOR WHITES FULL MODEL: R-SQ. = .76 p = .0003	1) Total network density	.018	.40
	2) Advice	.002	.09
	3) Time in relationship	.081	.06
	4) Gender (M=1; F=0)	.489	.08
	5) Type of dialysis	.692	.06
	6) Equal reciprocity	-0.008	.04
	7) Multiplexity	.006	.03

Table 48. Regression models for dependent variable--POMSNEG (negative moods--low levels desirable).

DEPENDENT VARIABLE: POMSNEG	PREDICTOR VARIABLES	PARAMETER ESTIMATES	PARTIAL R-SQUARE
NET MODEL: R-SQ.= .27 p =.0037	1) Relation intensity 2) Number of Relatives 3) Frequency of contact 4) Total network density	-21.66 -1.63 -.12 -0.44	.11 .06 .06 .05
FULL MODEL: R-SQ.= .35 p = .0025	1) Relation intensity 2) Church attendance 3) Frequency of contact 4) Number of relatives 5) Total network density 6) Multiplexity	-24.68 -22.22 -0.12 -1.20 -0.40 .31	.11 .07 .05 .05 .03 .03
FOR BLACKS NET MODEL: FULL MODEL:	No variable met .15 significance level for either model.		
FOR WHITES NET MODEL: R-SQ. =.66 p = .0006	1) Relation intensity 2) Frequency of contact 3) Total network density 4) Emotional support 5) Number of acquaintances	-50.356 -0.149 -1.268 -0.153 -2.430	.18 .15 .09 .19 .05
FOR WHITES FULL MODEL: R-SQ. =.56 p = .0001	1) Relation intensity 2) Frequency of contact 3) Church member 4) Number of relatives	-43.963 -0.184 -37.806 -1.818	.18 .15 .15 .08

Table 49. Regression models for dependent variable--Health Satisfaction (high levels desirable).

DEPENDENT VARIABLE: HEALTH SATISFACTION	PREDICTOR VARIABLES	PARAMETER ESTIMATES	PARTIAL R-SQUARE
NET MODEL:	1) Time in relationship	.032	.15
R-SQ.= .23	2) Advice	.001	.07
p = .0024			
FULL MODEL:	1) Time in relationship	.010	.14
R-SQ.= .55	2) Attend church	.414	.09
p = .0001	3) Emotional support	.002	.05
	4) Age at Onset	.022	.06
	5) Total network size	-.024	.07
	6) Years on current dialysis	.048	.05
	7) Help from network	-0.001	.03
	8) Number of strong ties	.029	.03
	9) Gender (M=1; F=0)	.192	.03

Table 49--continued.

DEPENDENT VARIABLE: HEALTH SATISFACTION	PREDICTOR VARIABLES	PARAMETER ESTIMATES	PARTIAL R-SQUARE
FOR BLACKS NET MODEL: R-SQ.= .11 p =.0980	1) Reciprocity in favor of patient	-.005	.11
FOR BLACKS FULL MODEL: R-SQ.= .62 p = .0002	1) Attend church 2) Gender (M=1; F=0) 3) Time on current dialysis mode 4) Relation intensity	.857 .290 .125 .255	.36 .09 .10 .07
FOR WHITES NET MODEL: R-SQ. = .54 p = .0009 FULL MODEL: Identical to NET MODEL	1) Time in relationship 2) Emotional support 3) Equal reciprocity	.050 .001 -0.007	.33 .09 .12

Table 50. Regression models for dependent variable--Life Satisfaction (high levels desirable).

DEPENDENT VARIABLE: LIFE SATISFACTION	PREDICTOR VARIABLES	PARAMETER ESTIMATES	PARTIAL R-SQUARE
NET MODEL:	1) Relation intensity	.153	.15
R-SQ.= .48	2) Frequency of contact	.001	.11
p = .0001	3) Time in relationship	.023	.05
	4) Multiplexity	.005	.08
	5) Help	.001	.07
	6) Number of Friends	-0.017	.03
FULL MODEL:	1) Relation intensity	.091	.15
R-SQ.= .56	2) Frequency of contact	.001	.11
p = .0001	3) Church member	.194	.09
	4) Time in relationship	.029	.05
	5) Multiplexity	.006	.05
	6) Network help		.04
	7) Race (W= 1; B= 0)	-.246	.05
	8) Number of Friends	-.017	.03

Table 50--continued.

DEPENDENT VARIABLE: LIFE SATISFACTION	PREDICTOR VARIABLES	PARAMETER ESTIMATES	PARTIAL R-SQUARE
FOR BLACKS NET MODEL: R-SQ.= .35 p = .0050	1) Relation intensity	.292	.28
	2) Help	.0009	.07
FOR BLACKS FULL MODEL: R-SQ.= .55 p = .0003	1) Relation intensity	.438	.28
	2) Church member	.418	.17
	3) Time in present dialysis mode	.080	.10
FOR WHITES NET MODEL: R-SQ. = .65 p = .0006	1) Time in relationship	.047	.23
	2) Multiplexity	.007	.13
	3) Reciprocity in favor of patient	.007	.14
	4) Advice	.001	.10
	5) Frequency of contact	.0009	.05
FOR WHITES FULL MODEL: R-SQ. = .89 p = .0001 (partial R-SQ. do not total whole R-SQ. due to rounding)	1) Time in relationship	.038	.23
	2) Type of dialysis	.642	.14
	3) Reciprocity in favor of patient	.005	.18
	4) Multiplexity	.007	.23
	5) Advice	.0005	.04
	6) Age at onset of ESRD	.020	.02
	7) Years with ESRD	.035	.02
	8) Total network density	-0.007	
	9) Number of friends	-0.016	

CHAPTER 7
DISCUSSION AND CONCLUSIONS

I learned a great deal from this study, both about what it is like to be a dialysis patient and about the influence of social structure and social network members on health outcomes.

Summary of Findings

Below are the important findings in this study:

1) There were no significant differences in dialysis populations by age, race, sex, marital status, education, income, age at onset of dialysis, church attendance.

2) There were significant*** differences between blacks and whites in frequency of church attendance. Blacks attend much more frequently.

3) HD patients had average lower status occupations before ESRD than did PD patients. This means that HD patients would be less likely to work after ESRD because they couldn't go back to the strenuous jobs they had been doing.

4) HD patients contact their network members much*** more frequently than PD patients do and blacks contact their

network members more* often than white patients do, regardless of dialysis mode.

5) HD patients have known their network members longer* than PD patients have known theirs.

6) Relatives are seen much*** more frequently than friends, who are seen much*** more frequently than acquaintances. Although not significant, PD patients had more relatives, friends and acquaintances than did HD patients. Also, white patients cited more network members than black patients did.

7) Blacks have significantly*** more "close" relations than do whites and those relations perceived by the informant as "closer" are seen more frequently than others.

8) PD patients have more* reciprocal relations than do HD patients and HD patients feel they "give more" to their network members than they get in return.

9) Social support, as measured by the Myers instrument, is confusing but PD patients have more "support" as measured by this instrument.

10) PD patients had larger networks than did HD patients. PD patients also had a larger number of strong ties than HD patients.

11) HD patients' whole networks and networks of relatives were more dense than PD networks. However, PD patients' network of friends and network of others were more

dense than those of HD patients. The only significant differences were for the friends networks.

12) PD patients are more "connected" than HD patients because PD patients have a greater number of relations who know each other, but this is not statistically significant.

13) Classification of network members was very difficult because categories are fluid. No seatmates appeared in these networks and very few caregivers.

14) A dialysis diet is hard to follow, especially for HD patients. Social network members can help or hinder the patient in complying with medical regimens.

15) There are some significant*** differences in serum blood chemistry values for PD and HD patients. There are some correlations between blood chemistry values and social network variables which indicate that the total number of relatives and the density of relatives and number of important people (strong ties) in a network are very important in predicting health outcomes.

16) Although non-significant, PD patients reported having more physical symptoms than did HD patients. Women reported having more symptoms than men did and white patients reported more symptoms than did black patients.

17) PD and HD patients rated their health exactly the same and were virtually the same in how satisfied they were with their health. PD patients were more satisfied with their lives in general. However, they reported more*

problems with life situations, such as their social life and sex lives.

18) As found in other studies, all dialysis patients experienced some depression. There was a significant** correlation between depression and total network density, with depression being lower for patients with denser networks.

19) The "locus of control" construct did not distinguish between HD and PD patients, who normally are thought of having as different locus of control. The only difference* was between that of CHLC, which is the idea that luck is influencing life. PD patients thought luck influenced their lives more*** than HD patients did.

20) There was practically no difference in positive or negative moods between dialysis populations. However there were some slight racial differences in the amount of negative moods of informants, with whites, especially males, having more negative moods, but not significantly so. White females appear to be most adjusted to dialysis.

21) Church membership, race, total number of relatives in one's social network and total network density have something to do with lowering patients' negative feelings.

22) There were no differences between HD and PD groups as to how they viewed the future. Both groups also felt similarly in their feelings of dependency on others.

23) Multiple regression analyses with social network variables and sociodemographic variables have shown some power in predicting health outcomes, especially depression, satisfaction with health and satisfaction with life. Regressions done by racial categories were especially fruitful in predicting health outcomes.

24) Dialysis patients had much smaller social networks than healthy people. Comparison with previous studies of healthy individuals in Jacksonville, Florida reveal that healthy people had twice as many network members as did the dialysis patients in this study. These patients' networks looked more like the networks of Mexico City residents (also studied previously), but were still smaller than the networks of those interviewed in Mexico City.

Social Structure, Social Networks and Health

The social networks in which ESRD patients are embedded are important sources of help. As with any chronic disease, ESRD patients need their network members and do rely on their networks for physical help and emotional support. However, the structure of patients' networks are not the same. Some patients work, some see their friends regularly at church or in the neighborhood and some patients rarely have contact with new individuals. Some patients do their dialysis at home and some receive dialysis in the presence

of a large group of others. All these factors influence the structure of a social network.

Since HD patients go to a dialysis center on a regular basis, their seatmates could form a stable part of the social network. However, because the seatmates vary and caregivers take turns caring for all patients, very few intimate relations are formed. Seatmates didn't appear and caregivers were minimally captured by the network generators used in this study. It seems that fellow patients may help pass the time but are not individually an integral part of the social network. Caregivers and patients themselves sometimes talk about the importance of fellow patients, but it seems to me that the relation is a structural one, rather than a personal one. That is, the fellow patients are "structurally equivalent" and are likely to interact similarly with one another. Since patients sometimes die, change dialysis days and dialysis shifts and don't always sit in the same dialysis chairs, they are easily replaced in the structure of the network. They do perform a function: helping each other pass the time, helping monitor each other's dialysis treatments and giving help in getting the attention of a nurse for emergencies. But the particular person doing all this doesn't seem to really matter. Caregivers are also structurally equivalent for HD patients. Although there are some nurses whom the patients say, "really get the fluid off you" or "stick you roughly," most

caregivers are interchangeable as far as the patients are concerned. The exception to this might be for PD patients. During training and consultations over a period of time, a trust relationship seems to build between the PD patients and the caregivers, but this really depends on the attitude of the caregivers.

Noncompliance and Social Networks

Some patients want to avoid all notice that they have anything wrong with them and do not like to talk about their disease. This type of patient may deny even having the disease and be reluctant to comply with diet or medication requirements, resulting in being labeled an "uncooperative" or "unadapted" patient. ESRD patients can be irritable and anxious because of having the disease. These behaviors are part of the denial of having ESRD and adjusting to it (Fortner-Frazier 1981). However, as Buchanan and Abram (1984) point out, the judgment of adaptation is by the clinical staff, and not by the patient. The patient is adapting to the disease in a certain way, perhaps not as the caregivers would prefer. They challenge caregivers to look at adaptation as a process and try not to be judgmental or frustrated with patient progress. Positive, non-judgmental communication with patients and realistic caregiver expectations about patient behavior have been demonstrated

to have an influence on patient's eventual positive adjustment to their disease (Kaplan De-Nour 1981).

Some researchers argue for adherence rather than compliance (Caplan et al. 1977; Gerber and Nehemkis 1986). This implies a working relationship between the physician and the patient, taking into account the patient's life situations. Theoretically, if social network structure has an effect on health outcomes, it could be used to help with the problem of noncompliance. One of the major problems contributing to the problems of ESRD patients is diet. The ESRD diet can be very complicated and cumbersome, especially for HD patients (American Kidney Fund 1987).

The things people eat are culturally learned and it is sometimes hard to break those habits. This can be especially difficult when family and friends are eating things that the ESRD patient cannot. Ethnic populations have food prohibitions and habits of eating certain foods which can upset the delicate chemical balance which the ESRD patient needs to maintain. In addition, psychological factors can contribute to noncompliance. Sometimes people eat something they shouldn't just to show they, and not the disease, are "in control."

Using blood serum levels averaged from several health check-ups, Cummings et al. (1982) found that 30% of their informants took phosphate binders, 86% followed dietary restrictions, and 59% followed fluid restrictions.

Compliance was found to be situationally determined and was related neither to whether people believed they should follow restrictions, nor their knowledge of such restrictions. They hypothesize that perhaps patients rely on family members to insure that they follow dietary instructions. Indeed, social isolation has been correlated with noncompliance in hemodialysis patients (Procci 1978). Some studies have shown males to be significantly more noncompliant than females (Blackburn 1977; Oldenberg 1988).

I agree with the theory that family members can have an affect on patient compliance. It might be either a bad or good effect depending on a number of things. However, if a patient is embedded in a dense network of people who all have the same beliefs, then the patient will either have those beliefs or be at odds with the whole social network. Bott (1954) and Cubitt (1973) found network density to be important in determining the norms of a network. Cubitt says, "it is therefore the high density sector in which ego interacts most or which is most important to ego, rather than the whole extended network, that will be responsible for norm enforcement (Cubitt 1973:82). I expect that is why I found network density and especially density of relatives in the network to be correlated with serum blood chemistries. These chemistries indicate when a patient is not compliant with the caregiver's regimen. If patients are in a dense network of people who all know each other and the

patient, they are likely to know the medical regimen of the patient. Thus, in a dense network, it is less likely that the patient will be able to get by with noncompliant behaviors, if the network members are all aware of the desired medical regimen.

Hill (1988) discussed the fact that rural blacks and whites consume a lot of greasy and fried foods, pork (especially fatback), greens and salt. These items are not desirable in an ESRD patient's diet. Hill found that many blacks believe they know more about their bodies than doctors do and know what can help them get well. Hill (1988) found that over 30% of blacks said that the "self" ultimately healed the illness, not the doctor. The sick person, according to Hill's informants, is in a partnership with God to heal the body. If it is God's will, they will get well, since God, not the doctor, cures. Blacks pray for sick people even if the illness isn't severe. Hill found that 95% of rural blacks prayed for the ill, while only 45% of the rural whites did. In addition, the whites only prayed when the illness was severe. In my research, a large majority of black patients attended church services and believed that their fate was in God's hands. With these beliefs, it is possible that these patients would be likely to trust God, (or their own judgment and that of their immediate strong ties) more than the word of a caregiver.

Stack (1974) has shown that a network of reciprocity is vital in the survival of blacks in slum areas. This network was likely to include both relatives and friends. It seems obvious that social network members fulfill important functions for someone who is ill. It is the health beliefs of the patient and also those of the social network members, working interactively, which result in the particular health behaviors which a patient pursues. Health care providers are part of a patient's social network and they too have a capacity to influence a person's behavior. Social networks help a patient interpret and react to an illness. If a network is densely constructed (in that a large proportion of network members know each other) the network can be isolated from other perspectives on illness. The more "insular" a person's social network is, the more health beliefs and behaviors are likely to be consistent within the network.

McKinlay (1973:288) found that among people with dense networks, network members were more likely to rely on each other for medical advice and were not regular users of medical clinics. The close-knit network members could call on each other for lay medical advice which they used instead of going to the clinic. These members reinforced each other's norms and values. The researchers noted that the place of consultation was important. They claimed that it would be much easier to disregard the advice of another at

that other's house, rather than one's own. However, the close-knit members were likely to be in one's own household, where the consequences of disregarding the network member's advice might cause personal problems. This is the problem when family members have forbidden food around and even feed it to the patient. In order not to disrupt things, the patient eats the forbidden food or at least pretends to. In the present research, patient compliance with dietary restrictions seemed to be influenced by social structural variables, namely density, number of relatives and number of "important people" in the network.

Physicians should make an effort to understand a patient's cultural perspective on health beliefs, and insure that they are using the same terminology for the same illnesses and conditions. The strict diet an ESRD patient has to follow could be in direct conflict with how patients think they should take care of their illness. The patient has to decide whether to follow the dietician and physician, their own cultural knowledge, or a mixture of both.

Getting people to comply with medical regimens is easier if the health care workers don't try to tell the patients what to do. Caplan (1974:104) advocates the role of a "wise sister" whom people are likely to listen and pay attention to. "If she attempts to teach, her sociological closeness is immediately destroyed. Patients consider the nurse a sibling figure and they feel close to her." Often,

caregivers in dialysis centers try to tell the patient what to do instead of advising them and letting them make their own decisions. It would be a good idea to let as many of the "strong tie" network members as possible know about the medical regimen of the dialysis patient. Because network density was found correlated with better health outcomes, perhaps the network could be put to use in helping the patient conform because of the influence of the network of the patient.

It seems that social network attributes do affect physical and mental health outcomes and quality of life of ESRD patients. There are some differences between dialysis modes and health outcomes and there are also some similarities. However, the differences may be more individual, or based on gender or race. In this study, groups who had more network members and more dense networks sometimes had better health outcomes.

I wondered whether PD patients would have better health outcomes because they seem as if they have a more "normal" life. That is, they are not tied to a dialysis center 3 times a week. However, HD patients are more or less normal on the days that they don't dialyze. Perhaps that is why there were no overwhelming differences between HD and PD. Also, patients can often switch modes of dialysis depending on medical urgencies. In general, HD patients had more dense networks were less depressed and reported fewer

physical symptoms. Fewer symptoms may have been reported because patients tended to separate their time on dialysis from other times. Several patients clarified this point. For example, they might have nausea, dizziness, etc., while on dialysis but would not report it on the medical scale because they did not have those symptoms outside of the dialysis experience. Patients on PD had more strong-tie relations and more network members than did patients on HD. Dialysis patients do not have the same networks as healthy people. Although they see their network members just as often as healthy people, dialysis patients have much smaller networks. Thus, dialysis patients may be at a disadvantage if they need help from a network member and that help is unavailable. Overall, black patients had smaller networks than white patients did. Therefore, black patients and those patients on HD are at an even greater disadvantage. Dialysis patients have many things to complicate their lives and they have to think about things that ordinary, healthy people don't consider. Jacob told me he was concerned recently when he was in an auto accident.

> If I had been knocked unconscious and they didn't know I was a CAPD patient and they didn't use the proper sterile procedures, I might get peritonitis and die. Also, hemo patients have to worry about taking care of their arms. People not on dialysis don't have to think of things like that.

Social network members appear to have an influence on dialysis patients both structurally and individually.

Usually researchers in social support measure those two things together and call it social support. This can lead to confusing results. Researchers should do more research with individual structural variables and not combine variables into an index unless they are the same type of variables. The present research was an attempt to look at individual structural variables and their affect on health outcomes.

I found from my research that the social structure of networks have some degree of influence on health outcomes. I also heard stories of definite individual outcomes. One very important health outcome is staying alive. If dialysis patients can follow their medical regimens as much as possible, they have to potential to live longer lives.

Some Suggestions

There may be ways to cut the cost of dialysis, both in terms of money and the cost of human suffering.

Dr. Edwards said,

> dialysis for each patient costs about $25,000 per year. If we just provided the medicine they need to prevent kidney disease it would only cost about $2,000 per patient per year. These people can't pay for their treatment anyway, so why don't we pay the $2,000 instead of the $25,000?

This is a good idea but probably cannot be done unless national health insurance is implemented. Other ways to lower the cost of dialysis would be to enable patients to

comply with their diet. This would make them feel better and their dialysis times shorter because the HD machine would not have to work longer to get rid of dietary indiscretions. Relations with seatmates should be encouraged as much as possible. Granovetter (1975) found that people needed "weak-tie" network members as well as strong-tie members. These weak-tie members help get new information into the network which would not have been available without those weak ties. Patients may be embedded in dense networks which have only one kind of dietary information, and that information may be full of misconceptions. One way to foster seatmate relations is to organize discussion groups. Patients already talk in the lobby prior to treatments or clinic visits. Several patients said they would be interested in patient groups where they could talk about their mutual problems. It is important that any caregivers (if present) should only act as an advisor if asked. It would be helpful to have a counselor or therapist present also. Patients could be scheduled to arrive 15-20 minutes early (most do anyway) and they could have a group discussion about pre-planned topics or whatever the group would like to discuss. These discussions may even continue during dialysis if the patients desire. If possible, dialysis chairs should be in semi-circles to facilitate conversation. Most patients would not come to the centers at a separate time for a

discussion group. They do not want to be reminded of their disease on off-dialysis times and they also might have transportation problems and be unable to get to the center except for treatments. These discussion groups would be harder to accomplish for PD patients because their appointments are spaced throughout the day. Discussion times could be at a time when most patients could come. These discussion groups could help patients get the right information from each other. Patients would be more likely to listen to someone who has the same problems as they do and someone who is not trying to dictate their lives.

Caregiver burnout is a problem when caregivers get too close to patients and then those patients die. However, if caregivers do form stronger-tie relations with the patients, I believe it is more likely that the patients would listen and try to please the caregiver through regimen compliance. Therefore, caregivers and patients should be on the same schedule and there should be an effort to try to keep patients seated next to the same seatmates. This could help dialysis patients, their seatmates and caregivers develop stronger-tied relationships. In this way, caregivers and seatmates would have a better chance of influencing a patient towards adherence to medical regimens.

I believe it is important to take a social network profile of an incoming dialysis patient. Caregivers should find out who is in the patient networks (not just the

immediate family) and if those alters know each other. The network members should be asked to come into the dialysis center and discuss the patient's diet and medication, the importance of compliance and the important role the network members play in the health of "their" ESRD patient. This could be accomplished through home visits; however, Medicare regulations do not permit frequent home visits by caregivers. Researchers (Pattison et al. 1975; Llamas et al. 1981; Hurd et al. 1981) have been successful in using the network approach to modify behavior.

The cost of dialysis could be lowered if more dialysis patients went back to work after the diagnosis of ESRD. This would be difficult but could be facilitated by helping the patient to have less time at dialysis, less time in transit, and less time waiting for the bleeding to stop after dialysis. Caregivers use "Gelfoam" pads to stop bleeding but they are expensive and many times are not used unless absolutely necessary. Often the dialysis centers are out of these pads.

More patients should be on peritoneal dialysis. Many physicians are not willing to do this because they do not know enough about PD and do not want to spend the time with patients required to educate them about PD and to monitor the patient's progress. However, the results from this study show that PD patients were more satisfied with their lives overall. Peritoneal dialysis is more desirable

because it is done more or less continuously and does not produce strong adverse effects on the body as HD produces. It is more likely that PD patients will be able to go back to work because they are not tied to a dialysis center several times a week. There are some misconceptions and folklore which exist among the HD population concerning peritoneal dialysis which might prevent people from wanting PD. However, a campaign of information about PD which is accompanied by contact and discussion with current PD patients might be succesful in clarifing misconceptions. Discussion groups which periodically combine groups of PD and HD patients might be helpful in this.

During the course of my research I heard many stories of how social network members helped patients and even saved their lives. But some were not that fortunate. Many patients will die of ESRD and its complications. ESRD is a debilitating disease which is very expensive both in money and in personal anguish of patients and their social network members. But the social network members can contribute, both individually and structurally, to a better quality of life for people who depend on dialysis to live.

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BIOGRAPHICAL SKETCH

Gene Ann (Welden) Shelley was born on December 8, 1951, in Kokomo, Indiana. She lived in Kokomo until she married Bill M. Shelley on January 29, 1972. She and her husband both attended Purdue University. During this period she worked as a secretary, attended school and had two children. Gene studied English and anthropology and received her B.A., with distinction, from Purdue in 1980.

She and her family moved to Orange Park, Florida, in 1980 and for five years was employed as a legal secretary. During that time she had another child, was a religious education teacher, and a Cub Scout den leader. She wrote two newsletters and served consecutively as secretary, vice president and president of her neighborhood women's club.

She began graduate school in the Department of Anthropology at the University of Florida in the fall of 1985 and received the master's degree in May of 1988. She has published co-authored papers in Ethnology, Social Networks, Journal of Quantitative Anthropology and Archives of Surgery.

She has been doing secretarial work throughout her tenure in graduate school, but hopes to be employed as a social science researcher after receiving the Ph.D.

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.

H. Russell Bernard, Chair
Professor of Anthropology

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I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.

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May 1992

Dean, Graduate School